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Particular experiences: a psychosocial exploration of myalgic encephalomyelitis (ME) and its relationship with self, environment and the material world

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Particular experiences: a psychosocial exploration of myalgic encephalomyelitis (ME) and its relationship with self, environment and the material world

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A thesis submitted for the degree of Doctor of Philosophy

University of Bath
Department of Psychology

May 2015

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Abstract

Myalgic encephalomyelitis (ME), also referred to as chronic fatigue syndrome (CFS), is a symptomatically defined and debilitating condition that presents as a range of physiological and psychological effects. Post-exertional fatigue and ongoing low energy levels are cardinal features. Whilst ME-like conditions have been recognised for at least two hundred years, they have been characterised over recent decades by a fiercely contested debate as to whether aetiology is primarily psychological or physiological. ME sufferers experience profound changes to their self-perception, ability to maintain daily routines and activities and how they are perceived in terms of their capacity to carry out social roles, including illness-status. The contested aetiology results in-part from a climate of dualistic thought and the biomedical model upon which ME is treated and theorised.

Whilst the effects of ME on self experience have been investigated from various qualitative and quantitative perspectives, the primary purpose of this thesis is to develop a psychosocial framework from which to explore previously neglected dimensions of the effect of ME on self experience. Developing a psychosocial understanding of ME is in keeping with a turn towards post-Cartesian and non-dualistic thinking. The second interconnected purpose of this thesis is to address the role played by the material environment and objects and to conceptualise their importance and relation to self and how it is affected by ME. This is currently absent in the literature on ME.

Developing a psychosocial framework suitable for this purpose rested on a synthesis of Actor Network Theory (ANT) and a psychoanalytically influenced use of metaphor and metonymy. At the heart of this synthesis are the notions of *relational ontology* (Latour, 1997; DeLanda, 2002) and *assemblage* (Deleuze and Guattari, 1987; DeLanda, 2002; Hodder, 2012). A relational ontology focuses on the relations between disparate objects such as material artefacts, humans, other organisms and concepts and avoids prioritising any one ‘thing’ as more important than another. The notion of assemblage has emerged alongside ideas concerning complexity, chaos and indeterminacy and informs a vocabulary addressing the problem of causality, determination and the stability of social and psychological phenomena (Venn, 2006). As part of a psychoanalytically informed psychosocial framework these concepts enable an exploration of ME by bringing together disparate aspects such as everyday objects, experiences, symptoms and environments in a non-causal, non-dualistic and processual manner. The psychoanalytic element also enables an exploration of the

unconscious and irrational aspects of experience, which is most pertinent with regards to the effects of ME.

Thus, the premise of this research was to establish a psychosocial methodology and theoretical basis from which to explore the effects of ME on self experience. Moreover, this methodology was designed to engage with the complex, coincident and entangled nature of the symptoms, discourses, objects, material artefacts, environments and non-human organisms that ME appears to be comprised of.

Methods were developed which enabled the researcher to be with and explore the day-to-day life and routines of eight ME sufferers in their everyday environments over a six month period. This involved working with the ME sufferers taking part primarily in their own homes and spaces around their home which they frequented, such as shopping malls and even a cemetery; in itself novel in terms of qualitative research into ME. Of these eight sufferers, three were male [age range 49 – 65; earliest formal diagnosis of ME occurring in 2005] and five females [age range 25 – 63; earliest diagnosis 2002]. Two sufferers were in paid employment, one was retired and five were unable to work due to their ME. Due to the extensive nature of the data, only 3 case studies, two male and three female, were selected for in-depth analysis. Cases selected were those that most clearly illustrated central analytic themes.

Data comprised talk, audio-visual material and the affective responses of the researcher. Analytic methods were devised which initially adopted a thematic approach before metaphoric and metonymic equivalences were drawn between what ME sufferers discussed and aspects of the routines, objects and environments they were engaged with. This informed descriptions of how these things became networked, in an ANT sense, and how self experience was implicated. A key finding which emerged is the notion of *debilitating spaces*. This term captures the manner in which, for certain sufferers, the experience and hence the maintenance of ME was intrinsically enmeshed with their immediate physical environment. Further findings discussed include the way in which seemingly everyday objects such as food blenders can be co-opted by sufferers as a means of enhancing their self-experience in light of ME.

Overall, the findings of this PhD are discussed in terms of the success and applicability of that premise and its contribution to the field of psychosocial approaches. The key assertion is that the methodology enhances an understanding of ME and its effects, highlighting the variable

yet particular nature of ME and its effect on self experience and in incorporating the hitherto
unconsidered range of objects outlined above.

Chapter 1

Introduction, overview and structure of the thesis

1.1 Introduction and aims of this thesis

This introductory chapter provides an overview and rationale of the research represented by this thesis. The research focus was developing a methodology suitable for exploring the relation between ME, the self and the material world and the things in it from a non-causal, non-reductive perspective. I begin the chapter by summarising the effects and history of ME and why it presents as a contested illness that continues to evade distinct characterisation. I then provide an overview of my relation to and interest in ME and how this evolved into the methodology and methods explicated. Finally, I present summaries of each chapter, drawing attention to their salient features and, where appropriate, existing work that I have drawn on.

1.2 Overview of ME and its effects

Confusion and ambiguity has long surrounded what is currently known in the UK as myalgic encephalomyelitis (ME) (Smith & Wessely, 2014); a distressing and debilitating chronic condition marked primarily by fatigue of an unknown origin. In its acute phase, sufferers are often bed ridden. The course of the illness is unpredictable, remitting and relapsing. Reviews of an eclectic range of papers which explore ME often reflect the ambiguity associated with the condition in their opening paragraphs; for instance a diffuse symptomology and a contested history dating back to at least the 19th century. The exact aetiology of ME remains unknown, although it is increasingly discussed in terms of an heterogenous, multi-system illness (Myhill, Booth and McLaren-Howard, 2009; Deary & Chalder, 2010). Different hypotheses have been proposed concerning the origin of the condition, from immunological disorders to post-traumatic oxidative stress and yet the confused and confusing nature of ME continues to challenge contemporary understandings of health and disease (Poeschla et al. 2013).

Clinically, ME is characterised by disabling, unexplained fatigue that is not alleviated by rest and which persists for four months or more (Bayliss et al. 2014). Beyond fatigue, symptoms are wide-ranging and include headaches, cognitive impairment, pain, sore throat, unrefreshing sleep and post-exertional malaise. There are no positive

diagnostic criteria and instead diagnosis is by exclusion of other conditions. After what is often an acute onset many sufferers progress to a chronic trajectory and prognosis for recovery is variable.

The mainstays of treatments for ME in the UK are cognitive behavioural therapy (CBT), graded exercise therapy (GET) and pacing. CBT and GET are aimed at rehabilitation whereas pacing aims at adaptation to the illness (White et al. 2011). The aim of CBT is altering negative cognitions that are hypothesised as playing a maintenance role in ME, whereas GET seeks to engage the patient in gradually and consistently increased exercise with the hypothesis that under-activity leads to deconditioning and exacerbates the condition (Wessely, S., Nimnuan, C., & Sharpe, M, 1999). Pacing is based on the idea that ME sufferers have a depleted amount of energy to spend on activities and that management should involve ensuring expended energy remains within the available 'energy envelope' (Jason, 2008; Brown, Evans and Jason, 2013; Goudsmit et al. 2012).

The efficacy of these treatments is debated. PACE, the largest randomly controlled trial of CBT and GET to date in the UK, compared specialist medical care (SMC) to CBT and GET and pacing (White, Goldsmith, Johnson, et al. 2011). CBT and GET appeared similarly efficacious and both better than pacing or SMC. However, improvement rates for CBT and GET were 30% and 28% which means that the majority of sufferers showed little or no improvement. Moreover, Bleijenberg and Knoop (2011) claim that there is little empirical evidence for the proposed mechanisms underlying CBT and GET. Twisk and Maes (2009) state that CBT and GET are often counterproductive and have resulted in some sufferers experiencing worsening symptoms. Twisk and Arnoldus (2012) add that CBT and GET do not address objective measures such as oxygen uptake. Thus, the issues surrounding, and rationales for, CBT and GET appear to reflect an implicit psychologisation of treatment and hence an underlying pathology rooted in the mind.

Indeed, the debate that surrounds ME reflects confusion over the relationship between mind and body *per se*. Establishing whether the aetiology of ME and its antecedents reflect a predominantly psychological or physiological process has been an area of conflict for specialists and sufferers alike for over a century. However, Van Houdenhove, Van Hoof, Becq et al. (2009) report that sufferers attending either a

psychologically or biomedically orientated treatment centre displayed no significantly different psychopathologies.

Part of the issue with characterising ME appears to reflect not whether mind and body can be differentiated aetiologically but the belief that they can and should be differentiated in the first place. This reflects broader epistemological questions. Many of the aetiological issues and approaches to treatment revolve around the mind body dualism and especially the hegemonic status of the biomedical model; which implies that the mind and body can be treated separately and that, ultimately, mind can be reduced to biological processes (Nettleton, 2006).

Because no consistent physiological aetiology could be found, clinicians began to look to psychological aspects as potentially causal and to represent it as psychologically rooted (e.g. McEvedy & Beard, 1970; Abbey and Garfinkel, 1991; Manu, Matthews and Lane, 1992). Whilst the conceptualisation of illness-as-deviance, from sociological perspectives (Gerson, 1976) has waned, its presence clearly lingers around ME. A further issue is that ME is often co-morbid with psychiatric conditions such as major depressive disorder (Arnold, 2008; Van Houdenhove, Kempke & Luyten, 2010) and this raises a question as to whether psychiatric disorder promotes ME or vice versa.

These issues have led to the ongoing stigmatisation of the condition and delegitimisation in the eyes of sufferers and even some physicians and a contest between sufferer and physician to establish the true nature of the illness (Banks & Prior, 2001). The difficulties sufferers face because of this psychologisation, delegitimisation and uncertainty is that they struggle to access benefits and insurance and a socially warranted sick role (Dumit, 2006). The lack of a definitive diagnosis and the spectre of a psychological aetiology mean many sufferers come to experience rejection and delegitimisation from family and friends (Wendell, 1996).

So the history of ME is complex. Indeed, even the term 'ME' is contested and often appears synonymously or alongside CFS as ME/CFS. CFS, or chronic fatigue syndrome, is a term most widely associated with the history of conditions similar if not identical to ME in the USA. ME is most often used in the UK and reflects a somewhat different trajectory of nosological development. Lewis, Cooper & Bennett (1994) suggest that CFS is preferential to ME because it implies neither a specific neurological aetiology nor a homogenous phenomenon. CFS and ME are classified as distinct illnesses in the International Classification of Diseases (ICD-10). However, a

Joint Working Group Report (2001) indicates insufficient evidence for complete distinction between CFS and ME or delineation of subtypes.

Biomedical research concerning ME focuses on aetiology but not on what it feels like to experience ME. In contrast, much social scientific qualitative research has explored how ME is experienced. Approaches in this area include discourse analysis, narrative analysis, interpretive phenomenological analysis and grounded theory. Whilst this work is useful in enabling sufferers to describe what ME feels like, a tendency is to aggregate the voices of sufferers and generalise how ME is experienced. What has emerged are a set of themes or discourses that characterise the condition, including warranting knowledge claims about ME, offsetting psychological stigmatisation and how illness narratives are constructed (Guise, Widdicombe and McKinlay, 2007). However, no single discourse about ME has attained dominance and hence each discourse challenges the explanatory power of each other discourse (Tucker, 2004). The picture becomes more complex and confused, given that sufferers are increasingly able to access information about ME. The distinction between expert and lay knowledge becomes blurred (Horton-Salway, 2004) and a ‘gulf’ between the understanding of sufferers and doctors exists (Hossenbaccus & White, 2013).

However, the relationship between illness in general and society is equally complex. Illnesses do not simply unfold as objective entities affecting peoples’ health in a unitary manner. Instead, how illnesses are constructed reflects a complex relationship between various social, biopolitical and institutional discourses (Karfakis, 2013). Kleinman (1986) for instance describes how not only can symptoms originate in the social world but also how the body and society exist in a dialectic relationship such that the body becomes a site on which social anxiety is inscribed. The manner in which people seek professional help in light of illness and bodily-changes is also shaped by culturally distinctive illness beliefs (Ware & Kleinman, 1992). How illness is experienced is therefore a constantly shifting process that reflects the dialectic relation between the well-body and the ill-body (Paterson, 2001). Thus, an exploration of ME and its effects should ideally reflect the confused yet dynamic relationship between illness, the self and the body and the manner in which these are entangled with social and epistemological perspectives.

1.3 Journey towards the research premise

What struck me about ME prior to beginning my PhD studies, despite increasing recognition of its heterogeneous profile, was its implicit representation as a discrete illness entity. From a discursive perspective, establishing ME as an unambiguous object enables various discursive positions to be constructed around it. Indeed the mind-body dichotomy enables similar contrasting discursive work to be achieved (Cohn, 1999). But at the same time I recognised a conflict in that ME did not appear to exist in any easily explained manner. I came to think about the term ME as a necessary label, yet one which hindered attempts to understand the condition as much as it helped.

My experience of ME involved two consecutive long term relationships with sufferers, one of whom had almost recovered from the condition and one who developed it and was diagnosed during the course of the relationship. I had therefore engaged with much literature on the subject. My casual reading led me to observe that despite a lot of work being carried out on how ME affects self experience, there was nothing explicit on how ME sufferers negotiated their immediate material environment, given the debilitating nature of ME symptoms. This observation coincided with making alterations to my partner's house in light of her worsening ME symptoms. A second observation was that despite discussing both partners' life histories leading up to and including ME, there was no clear cause for their condition or its ongoing presence in the absence of any physiological pathology. This led me to question whether thinking about causes was the most useful way of addressing the problem.

These were the issues which laid the foundations for my research and which intersected with my existing interests in psychoanalytic theory. My research aim crystallised into developing a way of exploring the effects of ME on self experience and how this experience was related to the material environment and objects in it. I wanted to develop a perspective that incorporated psychoanalytic ideas because of their value in exploring the confusing, contradictory aspects of how ME is experienced. Most significantly, psychoanalytic ideas struck me as providing a means of negotiating the mind-body dualism that ME was stuck upon.

Given that it was impossible to identify a single cause for my partners' ME, I wanted to find a way of holding on to the messiness and complexity of the condition. Finally, because I had insight into two particular experiences with ME and because of the

generalising tendency I had noted in ME literature, I wanted to highlight what I came to term the *particularity* of ME experience; that each case of ME was as different as it was similar.

1.4 Ideas drawn on to establish the methodology

Ideas about the autonomous and unitary nature of the self have for some time been challenged by postmodern and poststructuralist notions of a more fluid self, determined by powerful, politically infused discourses (Hollway, 2007). Benwell and Stokoe (2006) for instance explain how essentialist approaches to self, including psychoanalytically inclined thinking posit self and identity as an internal, knowable product of mind. Lewis (2012) claims that staying with a predominantly constructionist view of self and assuming that experience reduces to and can be understood through the way that broad social discourses position people, or how individuals call upon discursive repertoires, overlooks dimensions of experience that transcend inside/outside and are extra-discursive. In other words these are the elements of experience that are unconscious, felt, preverbal, connect self with other and that are not easily representable through discourse. Given these types of critique, I looked for ideas that could accommodate thinking about self as simultaneously fluid and yet retained a sense of interiority. A self where the divisions between inside and outside in terms of social and psychological processes were less clear. Most importantly, I looked for a means of exploring the ways that people are often not clear on what motivates their feelings or behaviour. My research led to an area of investigation gathered together as *psychosocial approaches*.

Psychosocial approaches is an emerging yet distinct discipline representing an eclectic body of work engaging with non-dualistic means of theorising the relations between the social and the psychological. It draws on ideas from feminist studies, anthropology, post-structuralism, discursive and psychoanalytic bodies of theory and continental philosophy. Developing a psychosocial framework appeared apposite because it maintains the integrity of both the psychic and social aspects of a self and typically employ psychoanalytic principles to rethink existing models of human rationality and the notion of a unitary self.

Given a psychosocial framework, I then looked to a means of establishing commonality between all the entities that ME might involve, including any model of self that I developed. I explored sociological theory to establish how self had been

thought of in relation to materiality. It was perhaps no coincidence that over recent years there had been a turn to materiality in the social sciences, with new ways of exploring and reassessing the fundamental relations with material things being developed (Domanska, 2006; Sayes, 2014). My work therefore reflects this material turn.

I did not want to implicitly suggest ME was caused by any one antecedent. It was important to avoid assuming either a biological, social or psychological definition of ME as this would inevitably lead to an inherently causal model. This meant finding a way into the experience of ME with no prior conceptions as to what might be entailed. Actor Network Theory (ANT) appeared ideally suited (Callon, 1986; Latour, 1986; 2005; 2007; Law, 1986a; Law, 1992). ANT originated in the study of science and provided a model of technological organisation that rejected social relations as independent of the material world (Latour, 2005). The basic premise of ANT is to describe how human and non-human entities, referred to in ANT as actants (Latour, 1987; 2005), come together in networks where the interests of a focal actant or a problematic situation can be negotiated and resolved (Law, 1986b; 1992). ANT explores the translations that occur as actants effect and have effected their own and each other's identities and actions and how relations emerge and are maintained by actants ensuring each other's ongoing interests (Tatnall and Gilding, 1999).

The premise that appealed to me concerning ANT was that it set out by establishing a *relational ontology*. The basic tenet of a relational ontology is that no entity is fundamentally more important than another (Latour, 1997) and is premised on the idea that there is no such thing as the social, but only actors in associations with each other (Munir & Jones, 2004). Therefore, the social or any other apparent ontological category cannot be looked upon to provide an explanation for how things behave.

Apart from enabling me to give equal credence to, for example, the role that a virus and a specialist discourse may play in ME, a relational ontology implies that materially orientated events are always in a dynamic state of becoming *and* disintegration (Collinge, 2006). In other words, a dynamic complex system such as an actor network sometimes leads to areas of order and at other times disorder, depending on whether actants are associating or dissociating from each other. This notion appeared to reflect the dynamic, eclectic and complex relations between the things that ME was comprised of.

However, whilst ANT looks only to the surface of actants and brackets off recourse to the inner complexity of actants, be they human, pieces of rope or a PowerPoint presentation, I wanted to retain some interiority in terms of the way that the self was construed and experienced. It was important to reflect not only the subjective feelings mobilised by ME but also that people usually experience self as an internal and consistent entity, even if at times confusing. To achieve this, I looked more closely at psychoanalytic ideas and particularly notions of metaphor and metonymy as a way of grounding the association between self, body and the material world.

My reading had already explored the work of Freud, Klein, Winnicott, Lacan and many others. What I had taken away from this was an increasingly explicit move towards what Freud had implicitly theorised, namely that the processes of the unconscious appear to function in terms of metaphor and metonymy. For example, a major theme in psychoanalysis, that of *transference*, implies that the present is understood unconsciously in terms of the past. As Borbely (1998; p.923) notes, this use of metaphor extends its original linguistic conception to imply the metaphoric nature of mentation in general. Given that Freud (1900) had already rooted ego as a primarily somatic affair, I looked to contemporary work on metaphor that theorised the connections between body, mental development and the physical and material nature of the world. I encountered the seminal work of Lakoff and Johnson (1980a; 1980b; 1999).

Exploring the associations between the body, cognition, affect and the non-material and material entities that people encounter in the world using metaphor and metonymy opened up the possibility of considering how the different things that ME appeared to be comprised of were connected. Moreover, metaphor and metonymy appeared to provide a means of tracing how, from an ANT perspective, actants become *displaced* from place to place and across time and form. Metaphor and metonymy hence provide a language to describe the ongoing presence and effects of things that have been transformed and re-represented.

Thus, the final set of ideas I drew on concerned the metaphorical relations between self, space and other from the psychoanalytic perspectives of Freud, Klein, Winnicott, Stolorow and Atwood. I also drew on the work of Lakoff and Johnson in terms of the relation between body, thought and metaphor and the work of Schmitt, Stern and Mueller in terms of linguistic metaphors and metaphor analysis.

Drawing these various influences together enabled me to develop a non-reductive methodology capable of exploring the individual experience of ME and its effects on self and how these reflect associations with specific material environments and the objects in them.

The present research builds upon and extends ME research by:

- Developing a psychosocial understanding of ME in keeping with a general turn towards a non-dualistic understanding where the experience of the sufferer moves centre stage (Baker, Kale and Menken, 2002; Bracken & Thomas, 2001).
- Addressing the role played by the material environment and objects at the level of self.
- Informing advances in psychosocial theory by seeking to develop a multi-method methodology and analytical approach.

This rationale is formalised in the following research questions:

- How can material actants be used to explore the relationship between self and others for people with ME?
- How can metaphor and metonymy be used to explore relations between actants?
- Can ANT and metaphor be used to rethink how the body is theorised in ME?

1.5 Methods developed

To address the relationship between ME and self experience, the research visits with ME sufferers needed to employ *experience-near* methods. This entailed being in the home and everyday environments that were important to the sufferer or were implicated in their ongoing daily lives with ME. This approach is novel with regards to ME research. Ethnographic methods appeared to be suited to the task. As Owen (2014; p.13) notes:

“The core premises of ethnography are to use multiple methods so that the researcher can analyze a phenomenon from multiple angles and make links between different research materials and experiences.”

Beyond exploring the narratives of ME sufferers, my aim was to participate and observe in their everyday activities to shed light on how ME affected them and their ongoing, ordinary and everyday sense of self. The rationale for this was twofold. Firstly, from the ANT perspective, being in the everyday settings of ME sufferers

meant that I could observe actants and trace the associations between them. A longitudinal approach was adopted such that visiting the sufferer over an extended period would reflect the relapsing and remitting trajectory of ME. Visiting the sufferer five times over a six month period meant that I could follow actants by reflecting on my response to each encounter and use this response to inform questions that might arise and which could be followed up. This would not have been possible with stand-alone interviews. The second aspect of the rationale was that adopting a position as an actant in relation to the sufferer's experience of ME allowed me to develop a mode of reflexivity that could acknowledge my role in the research process, including the analysis.

Several threads of data were accessed and woven together. For each visit, a digital video camera was used, which enabled me to record discussions and the activities that the sufferer and myself engaged in and the material objects and environments that were implicated. As I was interested in using the feelings that the research evoked in myself and feeding them back in to the research process, after the visit I also recorded my affective responses using a Dictaphone. It transpired that several ME sufferers I worked with wrote to me, unsolicited. The writings included reflections, questions and poetry and were included as part of the research procedure and analysis. Using multiple methods enabled me to gain experiential insights into the activities that ME sufferers carry out to help manage their condition as well as a visual record of how they interacted with the material world.

My reading and reviewing of literature uncovered no ethnographically inclined studies of this nature, which points to the value of developing such approaches with regards to ME.

1.6 A note on terminology

Throughout this thesis I refer to the condition as ME apart from where primary studies which use the terms CFS or ME/CFS are cited. This is for two reasons. Firstly, it reflects the experience and history of the condition in the UK and secondly, and most significantly, all of the sufferers I worked with primarily referred to their condition as ME. My use of the term reflects an attempt to remain faithful to their accounts. But this decision in itself is contentious and highlights the challenges associated with making methodological choices concerning the study of ME and the challenge of writing about it (Robinson, 2003). In this vein, I also made an active choice to refer to

the people I carried out my research with and who experience ME not as ‘participants’ but as ‘ME sufferers’ or ‘people with ME’. This choice reflects textual consistency but primarily that I want the reader to hold in mind that ME sufferers are real people struggling under difficult circumstances and not objects of study that exist in an abstract, decontextualised life.

1.7 Summary of chapters

The final section of this introductory chapter provides a brief overview of all subsequent chapters. The developmental thread that runs through this thesis reflects a movement from existing theory to how this theory underpins methodological choices, how the methodological premise was translated into research methods and an analytical frame which is then exemplified through my analysis. I conclude with an evaluation of the methodological premises and how it contributes to an understanding of ME and as a psychosocial approach.

Chapter two provides a review of the biomedical understanding of ME. I discuss the issues associated with diagnosing ME, epidemiology and outline the significant areas of physiology that have been explored through an aetiological lens. This is situated in a historical context that illustrates the long and contested nature of the condition. Because ME can only be diagnosed by the exclusion of other conditions it is important to understand how it overlaps and/or is co-morbid with other illnesses. To this end I discuss ME’s relation to psychological disorders and questions about its psychological aetiology and relation to personality and cognitive styles. This is especially important because of the manner in which ME has historically undergone delegitimisation as an organic illness, with the implication that it is ‘all in the head’. For this reason, the thread that runs through chapter two concerns the mind body dualism implicit in ME and how it manifests itself not only in terms of a psychologised aetiology but also in terms of the main treatment-approaches, research epistemologies and the general confusion that exists around the condition. Despite the present thesis representing qualitative social scientific research, it is important to provide the reader with enough detail to convey not only the confusion around ME but also the intense biomedical research that has been involved and how, despite many areas beginning to converge on the idea that ME is founded on definite physiological anomalies, much uncertainty remains; uncertainty that lays the foundation for the type of non-causal, non-reductive approach that the present thesis adopts.

Given that ME disrupts one's sense of self and bodily unity, the self is at the heart of chapter three. I begin by situating ideas about self in relation to chronic illnesses from a general perspective, before focussing explicitly on how the self in ME has been explored in social scientific research. This complements the biomedical perspective of chapter two. Discussion of qualitative approaches to ME provides the reader with a sense of how ME is experienced but also some of the methodological and conceptual issues associated with existing research. A key assertion in this area is that illnesses do not affect the self in predictable ways but instead reflect complex arrangements of social, physiological and psychological factors. From this position I adopt a perspective on self that envisages it as a dynamic and contingent process that implicates the material world. I discuss the importance of psychoanalytically informed psychosocial approaches as a means of conceptualising and exploring the unconscious and confusing ways in which self can be experienced. The central theorists I draw on are Freud, Winnicott, Klein and Stolorow and Atwood. Overall, these bodies of psychoanalytic work enable the conceptualisation of an intermediate space that transcends the inner world of the psyche and the outer material world. Subsequent to psychoanalytic approaches to self I outline the central concepts of Actor Network Theory. ANT in conjunction with psychoanalytic ideas provides a means of exploring ME and self from an experience near and reflexive perspective. The final section of chapter three outlines existing work on spaces and places. Thinking about the relationship between ME sufferers and specific places such as their home is important because such places are already full of personal meanings, relationships and affects. Chapter three leads towards the notion of ME as contextualised in a dynamic, psychosocial space where various entities and experiences coalesce in non-causal ways.

Chapter four discusses my methodological premise in terms of how the methods of ANT were drawn on to provide a general heuristic to explore the world of ME sufferers. Having outlined psychoanalytic ideas in chapter three, the present chapter develops a specific focus on how metaphor and metonymy can be used to investigate the associations between actants. Part of this discussion focuses on how contemporary work links metaphor to primary somatic experience. This is important as it provides ways of thinking about the body in relation to ME and material environments and objects.

In chapter five I describe how I developed my methodology into ethnographically informed methods. I begin by outlining the ethical requirement of the research before describing the steps undertaken to recruit ME sufferers and the demographic nature of the resulting sample of sufferers I worked with. In the second half of the chapter I detail the analytical procedure I developed, including the utilisation of ideas on metaphor analysis by Schmitt (2005) and Mueller (2005; 2010). Where necessary, I draw on existing methodology and theory to justify my choices. I also refer to my data to illustrate the more complex aspects of the analytical process.

To retain the integrity of each sufferer's experience of ME and to represent the particularity of how ME is experienced, each of my three analytical chapters are organised around a particular sufferer. These are Bruce, Whimsy and Les; representing chapters six, seven and eight respectively. Beyond retaining the integrity of each sufferer's experience of ME, each chapter addresses one of each of my research questions as detailed previously. Thus, Bruce's chapter exemplifies the relationship between ME, self experience and the material world and objects in it and how I used ANT as an heuristic device. I describe how Bruce utilises certain objects and practices to offset some of the consequences of ME and to provide a productive sense of self. Whimsy's chapter focuses more explicitly on how metaphor and metonymy were used to trace the associations between actants and how the antecedents to her ME can be thought about in terms of coincidence and coextensivity. I also suggest the notion of *debilitating spaces* to capture how an environment can become entangled with ME in detrimental ways. Les's chapter discusses the relation between ME and the body and how metaphor provides a way of re-imaging the body in terms of its heterogeneity and its relation to places that Les visits. I discuss the unusual nature of Les's ME-onset in relation to his heart as a particular part of the body and how the anxiety associated with events becomes entangled with ME and daily routines. Where necessary and throughout these chapters I draw on other ME sufferers I worked with to further exemplify or make contrasts in terms of my analytical claims. It is important to note some overlap of analytical inferences across these three chapters. This is inevitable given the aims of my methodological and analytical premises.

Chapter nine entails three main aspects. Firstly, I present a summary of my main findings and how they contribute to an understanding of ME and psychosocial approaches. This is followed by a discussion and evaluation of central aspects of the

methodological premise, namely whether ANT and psychoanalytically inspired ideas on metaphor and metonymy were compatible and whether they were successfully synthesised and whether the relational ontology of ANT provided a useful way of symmetrising and exploring the many facets of ME. The final aspect of chapter nine involves outlining what I consider to be the potential limitations of the research and my personal reflections on the research journey. I finish by suggesting directions for further research that would extend the present study.

Chapter 2

Background to ME

2.1 Chapter overview

This chapter provides an account of the biomedical understanding of ME as well as a summary of its historical development and relation to psychiatric diagnosis. Biomedical literature was reviewed with a focus on the effects of ME and its hypothesised aetiology. An account of ME from this perspective provides a backdrop for ideas subsequently developed in this thesis. ME has a developmental history that conflates common-sense beliefs concerning what is a physiological or psychological symptom, such as fatigue, with specialist discourses, underpinning epistemologies and mismatched methodologies. Despite mounting claims that there is an organic basis to the condition, an implicit psychologisation exists which fuels the conflict between the subjective experience of ME and dominant discourses about it. The thread that runs through this chapter therefore concerns the centrality of the mind/body debate and the confusion that results from it.

2.2 Presentation of ME

ME symptomology is varied, including sore throat, fever, muscle pain, joint pain, headaches, malaise, painful lymph nodes, photophobia, irritability, cognitive impairment, forgetfulness, brain fog, sleep disturbances, muscle weakness, mood disturbances, orthostatic hypotension, nausea, digestive system dysfunction and recurrent flu like symptoms (Afari & Buchwald, 2003; Wyller, 2007; Courjaret et al. 2009; Fernandez et al. 2009). The cardinal symptom of ME/CFS is debilitating, ongoing fatigue which severely limits the ability of the sufferer to maintain or achieve a normal every-day life style (Fukuda et al. 1994).

2.3 Historical background to ME and nomenclature

ME is often used interchangeably with CFS or together as ME/CFS. Patients in the UK tend to prefer ME as a descriptor whereas physicians, especially in the USA, refer to it as CFS (Prins, van der Meer and Bleijenberg, 2006). These preferences reflect different biomedical research histories and experiences concerning ME over the last seventy years. However, conditions that resemble ME have been recorded for at least

two hundred years (Straus, 1991; Shorter 1993; Berrios, 1990; Wessely, 1990) but the terms ME and CFS have shorter, intrinsically linked histories.

From the 1930s to the 1950s many polio-like epidemics occurred across the world; in locations such as Iceland, the UK, South Africa and the USA. These epidemics, eventually recognised as atypical of poliomyelitis, became grouped under the umbrella-term *benign myalgic encephalomyelitis* (Acheson, 1954; 1959). However, given that many incidents were neither benign nor myalgic, the prefix *benign* was eventually abandoned; hence the appearance of *myalgic encephalomyelitis* (ME) in the UK. In 1959, the term *epidemic neuromyasthenia* was suggested, based on the symptoms of muscle weakness; *myasthenia* and *neurasthenia* (Henderson and Shelekov, 1959).

This terminology linked ME to a condition called *neurasthenia*; a fatiguing illness with symptoms of depression, headache and anxiety, identified by George Beard in 1869. For several decades neurasthenia was a legitimate and ‘fashionable’ diagnosis (Berrios, 1995). However, given changes in psychiatric nosology, advances in neurology and changing social conceptions of illness the diagnosis fell out of favour. By the early 1940s, cases of neurasthenia were interpreted as depression (Berrios, 1995; Wessely, 1990). Neurasthenia provides an often cited historical analogue to ME and highlights the difficulties reconciling illnesses with no definite organic basis as all in the mind.

CFS first appeared in 1988 in the USA as a result of the focus on the Epstein-Barr (EB) virus and the proposal that the early polio-like epidemics were similar to chronic EB syndrome (Holmes et al. 1988). Thus, ME and CFS have developmental histories in the UK and the USA respectively. Wessely (1991) also notes that in the USA, attention was focussed on EB whereas in the UK enteroviruses were a focal point.

Issues of nomenclature are intrinsically linked to the stigmatisation of ME as well as evolving biomedical understanding of the condition, given its association with neurasthenia and psychiatric diagnoses. The belief that ME may be psychosomatic or that psychological factors inform the onset or maintenance of the condition places it at the heart of the relationship between mind and body.

2.4 Definitions and diagnostic criteria

There is at present no positive diagnosis that can confirm or refute the presence of ME (Reeves et al. 2003; Harvey & Wessely, 2009). Because ME is neither a distinct nosological nor diagnostic entity and because the psychological symptoms overlap with neuropsychiatric syndromes such as somatoform and anxiety disorders and major depression, diagnosis is by exclusion (Fukuda et al. 1994; Prins, van der Meer and Bleijenberg, 2006).

Diagnostic criteria retain many features associated with early epidemic outbreaks resembling ME more than fifty years ago. More recently there have been attempts to produce definitive criteria. In America, Holmes et al. (1988) under the Centre for Disease Control (CDC) set out the salient clinical features of CFS as the basis for future epidemiologic and clinical studies and indicate conditions producing similar symptoms that should be excluded from diagnosis. One limitation with their criteria is that the description of the primary characteristic of fatigue is abstract and doesn't distinguish CFS from unexplained fatigue in general. The first British attempt to describe criteria by which to assess for ME in terms of research studies was conducted by Sharpe et al. (1991).

In comparison with the CDC criteria, the British [Oxford] criteria were specific for features of mood related symptoms, stipulating that mental functioning *must* be impaired whereas this effect *may* be a feature in the CDC criteria, but did not recognise any clinical sign or symptom as characteristic of ME. In 1994 updated CDC criteria appeared based on recognition of the ambiguity of neuropsychiatric symptoms and their potential to confound study results (Fukuda et al. 1994). As with the Oxford criteria, the emphasis was on a framework to foster a systematic research approach and to compare CFS with other populations such as those presenting no disorder and those with pre-existing conditions. These criteria also tried to take account of idiopathic cases of CFS. However, they did not specify which measures to use or provide empirically based scoring guidelines to diagnose CFS (Jason et al. 2009).

In 2003, an expert consensus document for ME/CFS was developed in Canada (Carruthers et al. 2003). The report viewed ME/CFS as an acquired organic, pathophysiological, multisystemic illness that occurs in both sporadic and epidemic forms. The Canadian criteria select cases with less psychiatric co-morbidity, more physical functional impairment and more fatigue/weakness, neuropsychiatric and

neurological symptoms than the 1994 CDC criteria (NICE guidelines, 2007). The Canadian criteria and report were criticised by NICE for lack of methodological data.

In 2011, Carruthers et al. published further criteria for ME, rather than ME/CFS. In comparison to the 2003 criteria, the six month waiting period needed before diagnosis was dropped. Fatigue was dropped from the label, given its ubiquitous and confusing nature and *post-exertional malaise/fatigue* (PEM) was relabelled as *postexertional neuroimmune exhaustion*. This development indicates an increasing belief in the physiological basis for the condition and increased knowledge of how various bodily systems are implicated.

This is exemplified by Maes, Twisk and Johnson's (2012) primary-care study which used CDC criteria and biomarkers to claim that ME, CFS and chronic fatigue (CF) are distinct categories and that ME/CFS should be divided into ME [with PEM] and CFS [without PEM]. However, Jason et al. (2012) asserts that when applied to a population meeting the 1994 CDC case definition, both ME/CFS *and* ME criteria appear to select a more severe subset of patients. Finally, a meta-analysis by Johnston, Brenu, Staines and Marshall-Gradisnik (2013) suggest that the heterogeneity of the condition may result from assessment methods, particularly that most heterogeneity reflects studies from self-reported symptoms in community-care study samples.

Overall, diagnostic criteria have evolved to capture disparate symptomology via an increasingly expansive and prescriptive list of diagnostic inclusions and exclusions. A further problem has been the conflation of psychiatric symptoms and whether they are co-morbid with, or result from, ME.¹ Whilst most non-psychotic disorders are not exclusionary for a diagnosis of ME, co-morbid psychiatric disorders must be accurately assessed if people with the condition are to receive effective care (Afari & Buchwald, 2003).

In summary, what ME is and how to recognise it represents the difficulty in characterising it biomedically and adds to its historic and implicit psychiatric stigmatisation. The relation of ME to psychiatric categories remains a moot point and

¹ The Canadian Criteria select more symptomatic individuals because the criteria insist on it. The problem is that if the number of symptoms required increases, rather than excluding psychiatric disorders, to achieve a 'pure' case of ME, the opposite is achieved. In other words extending the possible symptom pool increases the implication of psychiatric disorder.

further the stigmatisation of the condition and the respective roles played by mind and body.

2.5 Epidemiology and demographics

UK ME prevalence estimates range from 0.2 – 0.5% (Wessely et al. 1997; Kerr, Christian, Hodgetts, et al. 2007; Cho et al. 2009). The variation may depend on whether the study is community or primary-care based and the specific diagnostic criteria used for assessment (Jason et al. 1999; Ranjith, 2005; Johnston et al. 2013). Selection bias in reporting may also be a factor.

Gallagher, Thomas, Hamilton & White (2004) suggest that since 1997 diagnosis of ME has increased but against a background of little change in symptom reporting. They attribute this to increasing legitimisation of the condition as well as trends in diagnostic labelling. This indicates that cultural discourses about the condition may mediate its effects.

Most sufferers tend to be female, with prevalence estimates ranging from 2.5:1 ratio (Afari & Buchwald, 2003; Gallagher, Thomas, Hamilton and White, 2004) to 4.5:1 Reyes et al. (2003). The higher prevalence in females may reflect differences in referral patterns, illness behaviour and socio-cultural expectations of the female sick role (Richman, Jason, Taylor and Jahn, 2000). Pawlikowska et al. (1994) found that the relative risk of fatigue in women compared with men was 1.3; a figure similar to Sharpe et al. (1990). Jason et al. (2000) supports not only the higher prevalence of women with ME/CFS but also revealed they were more likely to report significantly more severe myalgia and poorer physical functioning.

Historically, ME appeared over-represented in the middle and upper classes, especially white females, leading to its association with high-achieving groups and the epithet *yuppie flu* (Wessely et al. 1998). However, the condition is found across different ethnicities and countries in varying degrees (Cho et al. 2009). Variable prevalence might be explained by factors such as access to healthcare and cultural mediation of the condition (Dinos et al. 2009). Wessely, (1998) explain variation as reflecting symptom-attribution and selection and referral bias rather than aetiology. However, variable prevalence represents the types of claim and counter claim commonly found in cross-cultural ME/CFS research in that Western illness-constructs and theoretical frameworks may not easily translate to other cultures and may lack local validity

(Paralika et al. 2009; Cho, 2009). In Brazil, unexplained fatigue is not certifiable for treatment, sick leave or benefits and may thus be viewed as everyday adversity not recognised as a medical disorder.

Average age of onset is 20-40 years, although children as young as 5 can be affected (Jones et al. 2004; Farmer et al. 2004; Lorusso et al. 2009). The condition is less apparent in children than in comparable adult surveys (Chalder et al. 2003) and some studies exclude children under 12 (Rangel et al. 2000). The condition can prevail for 25+ years (Fernandez et al. 2009). Estimates of recovery range from 0-66% but this depends on how recovery is defined (Adamowicz, Caikauskaite and Friedberg, 2014). Full recovery is unusual (van Geelen et al. 2007) with estimates for a full recovery ranging from 5 – 10% (Joyce, Hotopf and Wessely, 1997; Cairns & Hotopf, 2005).

In summary, epidemiological patterns may result from the study setting (Ranjith, 2005) with outcomes reflecting factors such as health care access, study context, diagnostic criteria, accuracy and completeness of medical records and cultural mediation which may or may not legitimate the condition. These factors add to the difficulty in characterising ME.

2.6 Overlap with other conditions

A key difficulty in establishing a diagnosis of ME is that its symptomological profile overlaps with many other conditions. Exclusionary medical conditions include hypothyroidism, sleep apnoea, narcolepsy, malignancies, unresolved hepatitis B/C, iatrogenic conditions, psychiatric disorder, alcohol or substance abuse and severe obesity (Mihirshahi & Beirman, 2005).

Hickie et al. (2009) suggests that chronic fatigue states share a common set of symptom domains readily identifiable in the community and at all levels of health care. Consequently, it is likely that they share common risk factors, pathophysiology and may therefore respond to common treatment strategies. Hickie et al.'s study draws attention to the link between risk markers, be they genetic, biological or psychosocial and symptomology.

Hamilton, Gallagher, Thomas and White (2009) make a case for linking risk markers to symptoms in prospective rather than retrospective studies in that different functional somatic syndromes (FSS) share a common pathophysiology and that ME can be considered as a discrete FSS, made up of different sub-phenotypes. Arnett and Clark

(2012) suggest that many conditions presenting fatigue as a primary symptom share a common inflammatory pathophysiology.

Overall, how to effectively compare across different subject populations and how to operationalise subjective constructs of bodily sensations and reconcile these with specific biomarkers appears to influence how ME is conceptualised. Consequently, there are difficulties reconciling the subjective experience of ME with the epistemological ground of biomedical science. Accordingly, there are issues in ensuring compatibility between the various specialist perspectives on ME and how it is experienced.

2.7 Aetiology: the biomedical perspective

Studies on ME/CFS propose several aetiological roots, which can be divided into predisposing, precipitating, and perpetuating factors (White et al. 2001), though no aetiological hypothesis has received consistent supporting evidence (Klimas & Koneru, 2007; Courjaret et al. 2009; Fernández et al. 2009). In the subsequent discussion I distinguish between the physiological and psychological aspects of aetiology to highlight the tension between these two areas.

2.7.1 *Infectious agents*

Because many ME patients report infections prior to onset, research has focussed on identifying a causal agent (Mihirshahi & Beirman, 2005; Lorusso et al. 2009). Evengard and Klimas (2002) conclude that various infections may trigger ME. For example, exposure to Coxiella B produced more fatigue and ME-like symptoms in exposed individuals, 10 years after exposure, than in non-exposed controls (Wildman et al. 2002). According to Chia et al. (2010) enteroviruses can persist in patients to produce ME like symptoms. Suspect infectious agents suggested over the decades include mononucleosis, cytomegalovirus, human herpes virus type 6 and 7, Borna Disease virus, various enteroviruses, Chlamydia and Mycoplasma species (Gold et al. 1990; Kitani, et al. 1996; Nasralla et al. 1999; Evengard & Klimas, 2002; Nijs et al. 2002; Chapenko et al. 2006; Beqaj, Lerner and Fitzgerald, 2007; Fernández et al. 2009). However, in many cases contradictory evidence is apparent with inadequate methodology, such as lack of strict controls (Dalakas, 2003; Vernon, Shukla and Reeves, 2003).

2.7.2

Immune dysfunction

There are many studies assessing the role of immune dysfunction in ME but often result in contradictory evidence (Afari & Buchwald, 2003; Mahrshahi & Beirman, 2005; Wyller, 2007; Fernández et al. 2009). Although ME can occur after infection, no consistent evidence supports an immunologic process in disease maintenance (Natelson & Lange, 2002; Natelson, Haghighi and Ponzio, 2002). A key issue is whether immunological changes result from an underlying aetiology producing the symptoms of ME or whether they occur because of psychophysiological changes caused by ME.

Amongst the more consistent evidence appears changes in T-cell activation (Lyll, Peakman and Wessely, 2003; Robertson et al. 2005; Wyller, 2007), an alteration in cytokine activity (Cannon et al. 1999; Jason et al. 2005; Fletcher et al. 2009) and decreased function of killer cells (Caligiuri, Murray, Buchwald et al. 1987; Maes et al. 2007; Whiteside, Theresa and Friberg, 1998). However, differences in diagnostic protocols and laboratory techniques may account for persisting claims that no consistent evidence exists for an aetiological role of immune dysfunction (Mahrshahi & Beirman, 2005). Morris and Maes (2013) suggest that phenomenological and neuroimmune similarities between MS and ME/CFS substantiate the view that ME/CFS is a neuroimmune illness. Despite this view, caution needs to be exercised. As noted by Natelson, Haghighi and Ponzio, (2002), because of the large number of potential immunological markers being investigated it is likely that some markers will appear statistically significant due to chance and not because of a genuine implication in CFS. This means that the choice of statistical analysis is critical in determining the salience of an immunological role in CFS.

A picture is emerging where contrasting laboratory sites and hence contrasting methodologies are as much an issue as the heterogenous nature of ME itself (Demitrack, Faries, Herrera, DeBrotta and Potter, 1998). Oddly enough, claims that a clearer understanding of the mechanisms of ME is needed to develop treatments that will cure most cases are not uncommon. This appears to be at odds with the evidence that ME is heterogenous, both in symptomology and pathophysiology, because it implies an implicit belief in a simple causal model of the disease process; an issue compounded by the variability of how ME is deployed in the literature.

2.7.3

Endocrinology

Often cited in relation to the neuroendocrinology of ME/CFS is the hypothalamic-pituitary-adrenal axis (HPA) (Cleare, 2003; Mitrshahi & Beirman, 2005; Fernández et al. 2009), which is implicated in an everyday sense in homeostasis (Tsigos, Chrousos, 1994) and in relation to the stress response *per se* and other extrinsic and intrinsic stressors (Chrousos, Gold, 1992). Several studies report HPA hypofunction in a significant proportion of ME patients (Van Den Eede et al. 2007; Van Houdenhove, Van Den Eede and Luyten, 2009). The question concerning HPA involvement is its causal relation to ME. Some evidence suggests neuroendocrine dysregulation in ME is secondary. For instance, Candy et al. (2003) asserted that changes in cortisol level, a feature of HPA function, could not be detected in patients with post-infectious mononucleosis fatigue, a risk factor for ME. Gaab et al. (2004) found changes in the HPA axis were more distinct in long term sufferers, although the study also points out that sample selection bias may have resulted in a lower than expected psychiatric co-morbidity.

However, Cleare (2003) concludes that on balance, there are enough robust studies to suggest some level of HPA hypofunction. But many factors affect HPA activity, such as psychiatric co-morbidity and sleep dysregulation (Mitrshahi & Beirman, 2005). The role of HPA activity therefore remains uncertain.

2.7.4

Neurology and neuroimaging

ME patients often show symptoms such as cognitive impairment and headaches implying a role for central nervous system (CNS) neurological abnormalities (Bested, Saunders & Logan, 2001; Afari & Buchwald, 2003). Chaudhuri and Behan (2000) claim that the fatigue experienced in ME is distinct from fatigue associated with neuromuscular disorders but similar to that found with disorders of the CNS, such as Parkinson's disease and multiple sclerosis. However, Schwartz et al. (1994) found no significant difference in magnetic resonance imaging (MRI) scans of CFS and normal controls but single photon emission computed tomography (SPECT) scans revealed areas of lower level cerebral blood flow in CFS patients compared with the healthy controls, individuals with AIDS related dementia complex (ADC) and unipolar depression.

Neuroimaging may be of limited use in the differential diagnosis of ME/CFS, given that other inflammatory vascular and encephalopathic conditions can appear clinically and radiologically similar. However, an example of the convergence of investigative methodologies is illustrated by Caseras et al. (2006). Functional magnetic resonance imaging (fMRI) suggested differences in the activation of the working memory network in CFS patients compared to healthy controls; Caseras et al. (2008) also used fMRI to demonstrate that ME patients may experience difficulties suppressing emotional states associated with subjective fatigue.

Ortega and Zorzanelli (2010) highlight how the visual presentation of imaging techniques provides ME/CFS some objectivity, despite the actual images *representing* a physiological process and not the process itself. Overall, a problem with imaging techniques is that they cannot establish causality but only represent a correlation between factors.

2.7.5 *Genetic studies*

In this area, the two main avenues of investigations are by clinical assessment of gene expression and the use of twin studies. Vernon et al. (2002) demonstrated testing blood for gene expression in distinguishing ME from non-ME subjects, although it is not clear how either the experimental or control groups were characterised. The characterisation of ME in terms of overlap with other conditions has also been a focus of genetics studies.

Fukuda et al. (2010) investigated the association between a specific gene and ME given that the gene had previously been suggested as implicated in schizophrenia, major depressive disorder (MDD) and bipolar disorder and that some of the symptoms typically observed in ME were also common in MDD. Results suggested a gene associated with ME may also play a role in the induction of various psychiatric diseases. This type of evidence represents an overlap between psychiatric nosology and an organic basis for ME. Morris et al. (2003) propose that the gene implicated above with MDD and schizophrenia is also associated with mitochondrial activity. ME involves depleted energy levels and because cellular mitochondria are involved in energy production there exists an intuitive link, with some substantiating evidence (Myhill et al. 2009).

However, Roy-Byrne et al. (2002) concluded that ME and depression do not appear to share a genetic co-variance and that the link between depression and fatigue in ME is more likely to be environmental in origin or due to overlapping case definitions. This supports studies that suggest a link between chronic fatigue and atypical depression; perhaps with a shared aetiology as in hypoactivation of the HPA axis. Overall, conclusions about the relationship between genetic antecedents to ME and an overlap with other conditions are uncertain.

2.7.6 *Autonomic dysfunction*

Several research approaches implicate abnormalities of the autonomic system (Suarez et al. 1999; Newton et al. 2007). Self-assessment of symptoms associated with autonomic dysfunction, such as autonomic diarrhoea can be correlated with objective measures such as baroreflex sensitivity, heart rate variability and orthostatic tolerance. ME/CFS sufferers show significantly more autonomic dysfunction than controls, although autonomic symptoms did occur in the control group and did not occur in all ME sufferers. There may thus exist some relation between dysautonomia and ME/CFS. Overall, the exact nature and degree of autonomic system involvement remains uncertain (Afari & Buchwald, 2003).

2.7.7 *Significance of biomedical aetiology*

The central issue in understanding ME is disentangling what is psychological from what is somatic, given that this is even possible. As Engel (1977; p.132) states:

“...the same words may serve to express primary psychological as well as bodily disturbances, both of which may coexist and overlap in complex ways.”

This complicates reconciling objective methods of body-function with subjective statements about how they are experienced, which are then applied to further subjects and which may result in a self-confirming tautology. It also assumes for instance that reports about autonomic function are *only* about autonomic function. This is not the case, given that body systems are fully integrated.

Questions that run through biomedical aetiology are about how subjective experience can be objectified and measured and how what may represent normal physiological function for one individual is abnormal for another. Added to this is the difficulty of separating out the various strands of physiological function to ascertain the weight that

each lends to the overall condition. In other words, delineating between normal functioning and ME is difficult. Added to this, different researchers in different sites use different diagnostic criteria to select cases. Methods may be poorly controlled. Overall, there are many issues concerning how or whether a consensus concerning ME characterisation can be developed. It is clearly not the case that ME exists as a discrete entity that affects people in characteristically predictable ways and for distinguishable reasons.

2.8 Aetiology: the psychological perspective

In this section I discuss the psychological issues associated with ME. As with the biomedical perspective, the evidence is varied and contradictory and ME has to be understood within broader debates about psychiatric diagnosis, especially how diagnostic categories develop and the stigmatising effect of psychiatric diagnoses.

The relation between psychiatric disorder, fatigue and physiology is complex. The main questions concern causality and co-morbidity and whether psychological conditions and specific psychological profiles lead to ME, arise from or are co-morbid with it. For instance, as HPA hyperactivity in major depressive disorder (MDD) is a consistent psychiatric finding and HPA function is implicated in ME, a common ground between biological and psychiatric disorder is implicated. However, according to Sharpe (2005; p.271):

“The defining feature that makes a diagnosis ‘psychiatric’ rather than ‘medical’ is simply that it is listed in the psychiatric diagnostic classifications of ICD-10 and DSM-IV.”

Deale and Wessely (2000) note that patients often complain of being given the wrong psychiatric diagnosis and Johnson, DeLuca and Natelson (1996) found that the type of judgment made regarding whether a symptom was coded as physiological or psychiatric considerably affected rates of somatisation disorder diagnosed in CFS patients.

For instance, White et al. (2001) indicated the complexity of classificatory relationships in a study of 250 primary care patients with infectious mononucleosis or upper respiratory tract infection. Various predictors of fatigue and mood disorders were investigated. Three diagnostic schedules were used; 1994 CDC, empirically defined fatigue syndrome and Oxford criteria. Results indicated that predictors of

mood disorder and fatigue were different. Empirically defined ME was strongly associated with a positive serological test at onset and physical deconditioning. Mood disorders were predicted by a premorbid psychiatric history, a high emotional personality score and social adversity. However, immunological, behavioural and personality factors changed over time. This study suggests that social adversity triggers mood disorders that may in turn cause fatigue, rather than ME itself. Biopsychosocial models of ME thus incorporate it's maintenance due to the interplay of beliefs, inactivity and symptoms (Harvey & Wessely, 2009).

2.8.1 *Fatigue*

Fatigue is ubiquitous in that it occurs in many psychiatric and medical disorders (Arnold, 2008). Iversen & Wessely (2003), state that fatigue does not easily fall into the remit of either medicine or psychiatry and also note a dual direction of causality between depression and fatigue with the presence of each worsening the prognosis of the other. May and Kline (1988) note that fatigue as a symptom is both vague and subjective and that as historically distant as 1921 it was declared that no objective measure of fatigue could be determined. Fatigue is one of the most common symptoms found in medical consultations and primary and community care studies (Harvey, Wessely, Kuh and Hotopf, 2009). Around 25% of people report fatigue as a symptom. Around 66% of people reporting fatigue lasting longer than 6 months will also be suffering from a comorbid psychiatric disorder. Taylor, Jason and Jahn (2003) and Harvey, Wadsworth, Wessely and Hotopf (2008a) suggest that psychiatric disorders increase the risk of later chronic fatigue. Thus, central to ME research has been its relation to psychiatric disorder and hence fatigue. Much research has addressed the relationship between fatigue, ME and psychiatric co-morbidity with one avenue of inquiry focussing on the relationship to antecedent factors.

However, there remain difficulties in characterising ME. Firstly, there exists an implicit division between mental and physical fatigue that appears to be based on the biomedical model. Whilst the problem of mind/body dualism in characterising ME has been widely noted, the problem might in-part maintain itself given this implicit assumption. There is also a question of how fatigue is operationalised. In questionnaires fatigue is commonly discussed in terms of energy and therefore as quantifiable. Secondly, the general recourse of such research is the standardised questionnaire, which usually relies on self-assessment. The appeal of such methods is

the collection of lots of information that can be quantified and statistically analysed. But the problem is that the inherent subjectivity of such measures fails to account for individual ME experience and it is difficult to appreciate where the objectivity that these methods claim actually lies. In particular, fatigue scales recommended for use by research studies are inadequate because they result in inaccurate representation of the severe fatigue required to meet the ME research case definitions and hence distort the profile and number of ME cases in the first place (Stouten, 2005).

Fatigue is central to ME experience and in diagnostic criteria but how to characterise it is far from clear. Some 100 years ago the notion of fatigue evolved from a distinct nosological category, synonymous with what may now be called depression, into a feature of other illnesses before eventually disappearing from psychiatric diagnostic manuals (Shorter, 2005). The role fatigue plays in ME, biomedicine and psychiatry opens a window onto the relationship between illness and diagnosis and suggests that exploring how an individual experiences and understands fatigue as part of their general milieu may be as beneficial as trying to establish it in categorical terms.

2.8.2 *Co-morbid depression*

Individuals with CFS often have high rates of lifetime and current depression (Afari & Buchwald, 2003). Thomson and Nimigon (2008) found in a community based study that 36% of individuals with CFS were depressed. However, despite CFS-sufferers often meeting diagnostic criteria for depressive disorder, their symptoms vary from classical depression (Johnson, Deluca and Natelson, 1999), manifesting without anhedonia, guilt, and lack of motivation (Wessely, Chalder, Hirsch, Wallace and Wright, 1996).

Gagnon et al's. (2002) community based study based on self-reports of chronic fatigue showed that having one or more medical condition was associated with an increased risk of depression, although it is noted that the methodological issue was that these were self-reports of fatigue and not clinical diagnoses of ME. Thus, illness and depression may go hand in hand and major depressive disorder is itself a complex heterogenous syndrome that is diagnosed and categorised on symptomology (Arnold, 2008). Griffith & Zarrouf (2008) state that there remains no conclusive test that can differentiate ME from MDD, although they assert that they are distinct entities.

Jason, Najar, Porter and Reh (2009) carried out a study of the ability of fatigue measures to distinguish between CFS patients assessed on the 1994 CDC criteria and separate patients assessed with MDD. The ability to distinguish between disorders is important, given the ramifications for intervention and treatment and given that some of the minor symptoms specified in the 1994 CDC can also manifest in MDD. Results indicated that all of the ME patients assessed previously on 1994 CDC were reassessed similarly on the same criteria. However, 38% [14 out of 37] of MDD patients were also assessed as having ME. There thus remains the question of heterogeneity and how diagnostic criteria are formulated.

Jablensky (2004) notes that with changes to diagnostic classification between DSM-III and DSM-IV, the preponderance of psychiatric co-morbid conditions, which are in fact separate entities, appears disproportionately high and that either such illnesses occur in clusters or classification cannot discriminate between spurious co-morbidity.

Questions about co-morbid depression and ME remain unresolved. Sharpe (2005) notes that the current lack of a precise and agreed pathophysiology for the condition means that any hypotheses about co-morbid psychiatric conditions are actually assumptions and therefore have to be viewed as alternative diagnoses.

2.8.3 *Pre-morbid psychiatric disorder*

Harvey, Wadsworth, Wessely and Hotopf (2008b) state that differentiating between explanations for the temporal relations between psychiatric disorders and ME has not been possible because previous research has been retrospective or cross-sectional in nature. They followed 5362 participants with different measures of personality, psychiatric disorder and fatigue levels collected over the first 43 years of their life. ME was identified via self-report. Results suggested that individuals reporting a diagnosis of ME had increased levels of psychiatric disorder, particularly depression and anxiety, prior to onset of fatigue symptoms and were more than two and a half times more likely of reporting later ME. It is suggested then that psychiatric disorders may be an aetiological risk factor for ME or that they have common vulnerability factors. For example, Fischler et al. (1997) found a high prevalence of generalised anxiety disorder (GAD) in their study of ME patients and suggest it may be a risk factor for developing ME.

The issues of personality and personality disorders in ME are important because of the manner in which personality intersects with common-sense assumptions about the condition and issues such as what constitutes being legitimately sick (van Geelen et al. 2007). This in-part results from the indefinite nature of the condition, its correlation with neurasthenia and the manner in which neurasthenia and subsequent manifestations of the condition have been stigmatised along psychological lines. The difficulty for example of separating a genuine case of ME from a malingerer raises the issues of the type of personality involved.

Traits such as perfectionism and neuroticism have been implicated in the condition (White & Schweitzer 2000; Masuda, Munemoto, Yamanaka, Takei and Tei, 2002; van Geelen et al. 2007; Fukuda, 2010). It has also been observed that depressive symptoms are more associated with neurotic symptoms in ME patients with depressive symptoms than in those without them (Taillefer, Kirmayer, Robbins and Lasry, 2003). An increased level of neuroticism appears to be the aspect of personality that it most consistently found in ME patients (van Geelen et al. 2007).

Metzger and Denney (2002) suggest that individuals with ME set themselves impossibly high levels of performance that may lead to the subjective experience of cognitive impairment. Åsbring & Närvänen (2003) suggest that patients appear to overstate the severity of their problems. But arriving at a consensus on what perfectionism represents is difficult.

Whilst Hamacheck (1978) distinguishes between normal and neurotic perfectionism, other theorists posit it as a uni-dimensional negative trait (Burns, 1980; Hewitt & Flett, 1991). In a study of 27 female CFS outpatients and 30 healthy controls Dearey and Chalder (2010) found a significant tendency for people with CFS to report more neurotic perfectionism. Valero et al. (2013) suggest that neuroticism is associated with CFS by the mediating effect of depression severity. However, their study may be biased by a clinical rather than community based sample population and findings differ from Kempke et al. (2011). The suggestion is that different measures of fatigue may have influenced findings.

In terms of premorbidity, Kato et al. (2006) found that higher emotional instability and self-reported stress level were associated with later CFS. Although this study used self-

diagnosed participants it is interesting because it connects stress, familial environment and personality via coping style with a genetic base. The connection between personality and psychiatric disorder is also interesting. CFS patients with psychiatric disorders scored higher on fatigue measures compared with CFS patients without psychiatric disorders (Fukuda et al. 2010). A finding that backs up previous studies (Cloninger, Svrakic and Przybeck, 2006).

In terms of personality and lifestyle Van Houdenhove, Onghena, Neerinckx and Hellin (1995) and Van Houdenhove, et al. (2001) concluded that *action proneness* and an overactive lifestyle may be one factor that may not only initiate and predispose an individual to ME but also to maintain it, although Christodoulou et al. (1999) found no predisposing personality traits.

Overall, it is difficult to draw conclusions between personality and ME and it is therefore important to connect personality as an abstract construct to behaviour and real-life environments. Van Geelen et al. (2007) for instance, claim that personality is an important factor to be studied but that factors such as the ever-changing life narrative that sufferers use to make sense of ME and give direction to their life could usefully be included as an aspect of personality. Nater et al. (2010), whilst suggesting that CFS is associated with an increased prevalence of maladaptive personality and personality disorders, note that it is important to think about how personality plays a role, for instance in interfering with treatment adherence or resulting in unhealthy behavioural strategies. Observations such as this point to the need to ground factors such as personality in the particular experience of the ME sufferer in question.

2.8.5 *Cognition, emotion and models of ME*

A key feature of ME is its variable effects on cognition, which include confusion, disorientation, cognitive-overload, short-term memory loss and decision-making impairment (Wyller, 2007; Cockshell & Mathias, 2010; Carruthers et al. 2011). In terms of attribution, Moss-Morris & Petrie (2001) note that CFS patients are more likely to make external attributions for the condition as well as cognitive distortions specific to their somatic symptoms. Chalder & Hill (2012) note that faulty cognitive processing of emotion may be a causal factor in vulnerable individuals. Rimes and Chalder (2010) suggest that people with CFS were more likely than healthy controls to perceive the experience and expression of negative feelings as a weakness. Oldershaw et al. (2011) found that CFS patients demonstrated poor emotion-state recognition and

poor attribution of emotion in self but not others, reprising previous findings that despite impaired social function, emotional recognition in others by ME patients is not impaired and that other factors are responsible for the impairment.

There is a clear overlap between cognitive and emotional aspects in ME. In this vein, Surawy et al. (1995) suggest a cognitive aetiological model that involves a pre-morbid character featuring an achievement-orientation and a cognitive bias towards suppressing emotion or viewing it as a weakness. These factors are rooted in childhood experience. Given this pre-morbidity, ME is precipitated by various psycho-social stressors and perpetuated by cognitive, behavioural and emotional styles and social factors. Whilst this model sets up a specific type of ME sufferer and roots it in the early developmental context, it is useful in that it implicates socio-cultural processes and leads to recognition of the broader context. External attribution of the condition to specific physical antecedents, such as a virus, and the emphasis on the somatic symptomology offsets concerns about psychiatrisation of the condition and legitimates it by reducing loss of self-esteem and personal blame. Moss-Morris et al. (2011) take the cognitive behaviour model further by incorporating a specific biological antecedent to investigate whether psychological factors could predict the onset of CFS following acute mononucleosis. Results suggested support for the cognitive behavioural model in that factors such as premorbid perfectionism are useful predictors for later CFS.

However, somatic attributions may increase symptom focusing or functional impairment Rimes and Chalder (2010). Poeschla et al. (2013) found that higher emotional instability and lower extraversion were related to chronic fatigue. The implicit psychologisation of CFS is present, given that they suggest:

“...behavioral prevention and intervention strategies can be used to mitigate or reverse the development and maintenance of CFS and other fatiguing illness.”
(p.296).

Models of ME/CFS are useful in bringing together psychological and organic factors. However, the weight of each factor is still under debate. Harvey & Wessely (2009) suggest an aetiological biopsychosocial model such that a combination of pre-morbid risk, followed by an acute triggering event leads to fatigue and subsequent behavioural and biological responses and CFS. Maes and Twisk (2010) criticise Harvey and Wessely's model in that the only biological component is the viral trigger whereas maintaining factors are ostensibly behavioural. The caveat is that recovery from ME

depends on addressing the behaviour and concomitant psychological factors. In contrast Maes and Twisk suggest a model where biochemical process and immune dysfunction is foundational at each stage. Treatment and recovery becomes a matter of addressing physiology as well as psychology. But the recurrent problem is that even with this model which acknowledges the complexity of ME/CFS and implies a complex biochemical foundation there is a wish to translate complexity into remedial and causal arrangements.

2.8.6 *Significance of psychological aetiology*

Models of ME and exploring aspects such as cognition and emotion are useful because these factors can be brought together with the physiological to provide a more holistic perspective. However, an issue is how to make compatible the various factors that ME is comprised of, such as physiology, pathogens, social discourse, psychological constructs. Given the disparate epistemological foundations from which ME research is approached it is easy to appreciate the apparent inconsistencies and confusion that characterise the condition. An approach to ME that can make compatible the various strands of knowledge about it would be useful and this appears to implicate broader discourses about biomedical science, psychology and culture.

Underpinning this are methodological issues regarding how to objectify and measure subjective experience. The preceding discussions imply that the overlap and relation between for example depression, personality and the expression of ME presents as a confusing picture. Specialist discourses of ME, whilst informing common-sense understanding, cannot capture or reflect the particular experience of ME.

2.9 *Treatment and management: CBT, GET and pacing*

In this section I review how ME is treated and managed, with a focus on CBT, GET and pacing. Whilst clearly important, I do not address pharmacological and alternative therapies because I feel that the main treatments and their development adequately illustrate my contention that the conceptualisation of the mind/body dichotomy is a sticking point in understanding the condition. The central theme is the way in which treatments polarise, albeit implicitly, around mind and body, resulting in an inherent psychologisation of the condition. GET, pacing and CBT appear to prioritise addressing the physical symptoms of ME and yet their efficacy arises from changing

the beliefs that patients hold about their symptoms and not physiological changes *per se*.

The uncertain aetiology of ME and the wide ranging symptomology means that no cure exists and the condition is instead managed; with cognitive behaviour therapy (CBT) and graded exercise therapy (GET) showing the best results (Rimes & Chalder, 2005). These approaches correlate with mind and body respectively. CBT has the aim of adapting and altering negative cognitions, assumptions and emotions that may prevent or hinder desirable or functional behaviours and activities. GET seeks to engage the patient in gradually and consistently increased exercise (Moss-Morris, Sharon, Tobin and Baldi (2005). In this sense, the recurring mind/body dualism that characterises aetiological debates about ME is reprised.

Both CBT and GET are based on behavioural interventions. With GET, the patient is encouraged to decrease the degree to which they monitor symptoms to determine activity levels (Fulcher & White, 1998). Moss-Morris, Sharon, Tobin and Baldi, 2005) showed that focussing less on symptoms and increasing beliefs in treatment control correlated with decreased fatigue and increased physical functioning. This ties in with Paterson's (2001) assertion that the sense of control is vital to one's sense of well-being.

Similarly with CBT, post-treatment improvement has often been attributed to increases in activity level (Deale et al. 1997; Bleijenberg et al. 2003). However, Wiborg et al. (2010) found from re-analysis of three previous randomised control trial (RCT) studies that CBT did not result in an increase in physical activity at the end of treatment or an increase in physical activity associated with fatigue reduction. This reflects the theory that the positively altered beliefs that the individual holds about their condition is key. It also supports findings from an RCT by Wearden & Emsley (2013) that whilst activity-behaviour may change it is perhaps the underlying beliefs that are important. This remains the main-line of thought from the perspective of cognitive behavioural interventions. Wiborg et al. (2012) analysed the effect of introducing perceived problems with activity and sense of control over fatigue as mediators in a CBT based treatment protocol. Results suggested these mediators interact to reduce symptomology. However, some variables may not have been controlled and mediating factors were not assessed whilst treatment proceeded. A significant observation is the suggestion that CBT and GET therapists may want to de-emphasise the role of

physiological processes when they introduce the treatment rationale to patients. The implication which remains is the centralisation of the psychological aspects of ME.

Given the primary symptoms of fatigue and post-exertional malaise, questions exist regards whether rest or exercise is most beneficial. Nijs et al. (2008) hypothesized that using exercise limits would prevent symptom increase and worsening health status after a walking exercise in ME patients. They concluded that limiting the intensity and duration of exercise attenuated health status changes after exercise but did not prevent short-term symptom increase. Wessely and Powell (1989) suggested that avoidance of exercise may lead to physical deconditioning. This is supported by White and Fulcher (2002) who found that physical deconditioning may play a role in maintaining physical debility in ME patients. It is partly on this basis that GET was developed.

However, Bazelmans, Bleijenberg, van der Meer and Folgering (2001) conclude that physical deconditioning doesn't appear to be a maintaining factor in ME. Sisto et al. (1998) found a marked decrease in activity levels in 20 females with ME but much later than their self reports suggested. The authors propose that this may result from the patients incorrectly interpreting how they feel after exertion. This type of evidence appears to justify the GET approach but many sufferers report adverse effects resulting from GET.

Nijs, Paul and Wallman (2008) suggest that GET can be safely undertaken without damaging effects to the sufferer and that the issue was early GET approaches advocating continued exercise at the same level, with sufferers developing symptoms in response to the exercise. Maes and Twisk (2009) claim that exertion leads to malaise with decreased physical ability, cognitive impairment and increased musculoskeletal pain, suggesting that underlying pathophysiological mechanisms become amplified.

Pacing is essentially a behavioural intervention where the patient acknowledges the typical fluctuations in symptom severity and delayed exercise by setting daily activity and rest goals to avoid exacerbations (Nijs, Meeus and De Meirleir, 2006; Nijs, Paul and Wallman, 2008; White et al. 2011). White et al's RCT compared specialised medical care (SMC) with pacing, CBT, GET/SMC and SMC alone. SMC consisted of an explanation of CFS, generic advice and symptomatic pharmacotherapy. Results suggested that SMC with GET and CBT were more effective in reducing fatigue and improving physical functioning than SMC alone. The most interesting outcome was

that results were the same for participants meeting various CFS criteria and for those with depressive disorder. As such, any conclusions about treatment efficacy have to be qualified with a consideration of methodological issues (Whiting, Bagnal, Sowden, et al. 2001).

It is also important to note that cognitive [and biomedical] approaches to understanding ME assume that sufferers' illness attributions reveal the meanings sufferers attach to symptoms, disabilities and bodily signs (Horton-Salway, 2001). These attributions are then seen as influencing sufferers' illness behaviours, coping responses and emotional reactions (Lipowski, 1969, 1974; Kennedy-Moore & Watson, 2001; Vandenberg et al. 2009; Rimes & Chalder, 2010). This premise forms the basis for cognitive behavioural therapy as a treatment for CFS sufferers (Wessely & Powell, 1989; Wessely, Butler, Chalder, & David, 1991; Abbey, 1993; Corstorphine, 2006; Hambrook et al. 2011) *and* explanatory models of ME (Surawy, Hackman, Hawton & Sharpe, 1995).

In terms of 'management' of the condition, Van Houdenhove and Luyten (2009) state that there is no consensus about the final treatment goal in ME and view coping versus recovery as a faulty dichotomy. But despite positing ME as a stress-system failure, the psychiatrisation of the patient is still apparent in statements such as:

“Changing energy-consuming lifestyles and habits such as maladaptive perfectionism, and learning to prioritize life goals may maintain gains and prevent relapse.” (*ibid.* p.153)

In summary the preceding discussion emphasised the implicit psychologisation of ME and therefore the division between mind and body from the main treatment perspectives. The manner in which mind and body remain conflated in terms of what is driving treatment protocols and how they are conceptualised is entangled with a dominant psychologising discourse. Because ME is not a discrete entity and because it transcends social, psychological and physiological processes it cannot be characterised easily and hence cannot be cured. Rethinking the mind/body dichotomy in a way that dissolves these boundaries may be useful.

2.10 Chapter summary

The pivotal problem in the ME debate appears to be whether the condition reflects a primarily somatic or psychological aetiology. Because of the broad symptom profile and diagnosis by exclusion, disentangling what is psychological from what is somatic is difficult. This problem also reflects difficulties in establishing and reconciling objective methods of measuring impairment with subjective reports of symptoms such as fatigue. Despite criteria being developed to aid research and standardising diagnosis, the picture remains unclear. Added to this is the issue of assessing what represents normal physiological function in the first place and that different researchers using different methodologies and representing different epistemological perspectives produce often conflicting results. Whilst various cognitive and biopsychosocial models of ME have been developed there remains uncertainty about the roles played by antecedent factors and how the condition is maintained. However, such models are useful in bringing together the various threads that constitute ME. The inherent psychologisation of ME characterises the condition as well as treatment approaches such as CBT and GET and this is reprised in the stigmatisation that sufferers seek to avoid. The relation of ME to psychiatric conditions is also unclear, for example whether depression represents a primary symptom or secondary symptom.

What needs to be held in mind is a sense of the confusing nature of ME and the intricate relations between mind, body, diagnostic classification and how these are influenced by the epistemological foundations of biomedical and psychiatric medicine. However, what biomedical explorations do not reveal is what it is like to suffer ME and how suffering affects one's sense of self. With this in mind, chapter three outlines how the relations between chronic illnesses such as ME and the self have been approached, before laying the foundations for a psychosocial framework from which to consider these relations.

Chapter 3

ME and the self

3.1 Chapter overview

The present chapter situates ideas about self in relation to chronic illnesses such as ME. I emphasise that illnesses are not necessarily experienced, nor affect self, in predictable ways. Instead, illnesses reflect a complex arrangement of social, physiological and psychological factors that necessitate a reassessment of self as an ongoing dynamic and contingent process. I give consideration to the relationship between self and the material world of objects and places; an aspect that has been overlooked in existing ME research. Considering the relation between self and objects is important because it is through objects that the self can affect and be affected by the world.

To frame the way that ME and self are mutually implicated I then outline the importance and use of psychosocial approaches. This is an emerging yet distinct discipline within the UK and elsewhere which now has learned society status. Psychosocial approaches represent an eclectic body of work that engages with non-dualistic means of theorising the relations between the social and the psychological and encompassing a range of ideas from across the social sciences. A psychosocial framework is apposite because it maintains the integrity of both the psychic and social aspects of ME.

Typically, psychosocial approaches use psychoanalytic principles to rethink existing models that emphasise or rest on human rationality and the notion of a unitary self (Clarke & Hogget, 2009). Psychosocial approaches challenge the preoccupation with language and cognition, instead paying attention to feelings and affects and enabling new conceptualisations of the boundaries between inner experience and outer reality and how self is experienced. This is pertinent, given the contested nature of ME and the relationship between mind and body. Because ME can be experienced in ways that involve a confusion of mind and body, I turn to psychoanalytic ideas in relation to notions of the self. These ideas enable thinking about how the unconscious aspects of ME might affect self experience. Psychoanalytic ideas are also discussed as a means of establishing a psychosocial space in which to consider the relationality of self, others, material objects and the everyday environments that ME sufferers negotiate. To

identify and trace the associations between self, places, objects and others I outline Actor Network Theory (ANT) and explore how it encourages relational thinking. Focussing on ontology and synthesising ANT with a psychosocial framework provides a way of bringing together the different entities that might be implicated in the experience of ME. These include symptoms, beliefs, viruses, environments and material objects. I describe how a 'relational' ontological stance is adopted and why this enables acknowledgement of the heterogeneous, particular nature of ME. As ME affects sufferers ability to engage with objects and places, I review work that has focussed on the relationship between health and places such as the home. Bringing the relationship between ME sufferers and specific places such as their home to the notion of a psychosocial space is important because of the way that such places are already filled with meaning and affective intensity.

3.2 Chronic illness and self experience

In this section I consider the effects of chronic illness on the self from the perspective of social scientific health research and connect this to more general questions about how self is constituted. Chronic illness does not unfold as a set of discrete illness symptoms that affect the self in an objective manner. Instead, illness symptoms interact with the socially constructed nature of illness, including personal and professional beliefs about illness, and disrupt the unity of mind and body. I argue that exploring a condition such as ME, which is marked by aetiological questions revolving around the mind-body dualism, requires a perspective on the self and its relation to ME that transcends characterisation as psychological, social or physiological. Such a perspective requires consideration of the role played by non-human objects, given that it is partly through the semiotic system afforded by objects that self is constituted

Qualitative social scientific work that investigates health is important because it complements and enhances clinical and biomedical approaches by providing insights into sufferers' perceptions of the aetiological processes underlying conditions such as ME (Smith, 1996; Turpin et al. 1997; Van Houdenhove, 2002). According to Jelbert, Stedmon and Stephens (2010) the aim of qualitative health research is to understand and represent the experiences of sufferers by interpreting the meanings that illness phenomena hold for them. Qualitative work seeking to understand the effect of ME on the self is especially important because the condition is marked by aetiological, terminological and diagnostic ambiguity and social misrepresentation (Clements et al.

1997). These already complex factors converge with sufferers beliefs about the condition to the extent that their whole life world, including how their relations with others and physical daily functioning, appears to be affected (Wessely, 1999; Prins, van der Meer, & Bleijenberg, 2006). This is especially true of ME, given that mind or body explanations raise delicate issues about sufferers' identities and credibility (Horton-Salway, 2001; 2002). It is not the case that ME exists as a discrete disease entity that can be investigated objectively. Thus, the development of the self in general, and especially in light of ME, is fundamentally interpersonal in nature and bound up with the development of the person as a social being (Charmaz, 1983; Andersen & Chen, 2002; Wood, Littleton and Oates, 2002).

Kleinman (1986) and Charmaz (1995) for instance explain that illness symptoms interact with social context to produce a mode of being that involves a dialectic relationship between mind and body. Thus, by examining the social construction of illness it is possible to think about how social forces shape the illness response and self experience (Eisenberg, 1977; Charmaz, 1995). However, ME presents a problem because it challenges the delineation between the roles of being healthy and being legitimately sick²; due to a lack of definitive biomedical evidence of organic pathology, sufferers cannot easily validate their right to be legitimately ill (Robinson, 2003). This exacerbates the manner in which ME destabilises how self is experienced.

Chronic illness presents a threat to the integrity of self and can only be managed, rather than cured (Cooke & Philpin, 2008). It disrupts assumptions about how one's body functions and also the sense of wholeness of body and self that might otherwise be taken for granted (Charmaz, 1994; 1995). Because conditions such as ME run disruptive, unpredictable and variable courses (Lubkin & Larsen, 2002), ME sufferers are obliged to adopt, adapt and reassess trajectories of self-development as an ongoing dynamic process (Charmaz, 1995; Clarke & James, 2003; Whitehead, 2006; Larun & Malterud, 2007; Brocki, 2008; Vandenberg et al. 2009).

If chronic illness disrupts the wholeness of mind and body and if social processes and the nature of beliefs about illness are entangled in complex ways, the implication is that self and the experience of ME is contingent. In general terms, Hollway (2007) alludes to the shifting, situated nature of the self of the present era as non-unitary, non-self-determining and not as an innate entity. Paradoxically, ME sufferers are often

² See for example Parsons (1951) on the 'sick role'.

positioned as responsible for aspects of their condition if they cannot demonstrate a clear, organic aetiology (Tucker, 2004).

An important field of thought that addresses the issues around the determination of self comes from poststructuralist and social constructionist thinking (Lewis, 2012). From these perspectives, self is constituted and shaped by broad discursive forces which are internalised to produce certain subjects (Foucault, 1982; 1997; Butler, 1993; Bunton, 1997; Burkitt, 1998; Hall, 2000). These subjects come to experience, talk about, understand themselves and are ordered through powerful discourses organised around normative categories (Lewis, 2012). In the case of ME, this occurs via specific medical and lay discourses that are dependent on knowledge that is not objective, neutral or value free (Arksey, 1989; Clarke & James, 2003). Thus, the 'ME sufferer' can be envisaged as a subject brought into being as a particular type of person.

ME is important because of the contested relationship between mind and body and its consequences for aetiology. Foucault (1977) placed the body at the heart of struggles between different discursive formations of power and knowledge. From this viewpoint, the body of the ME sufferer is a site on which the ME debate is inscribed and experienced. However, as Lewis (2012) notes, this poststructuralist conceptualisation of the discursively produced body and subject destabilises the modernist notion of a subject who can be scientifically scrutinised and categorised. This blurs the capacity for a bounded, bodily self and the manner in which the body and self can be known in any absolute sense (Bunton, 1997).

The fluidity of self is also relevant in an immediate way. Paterson (2001) for instance emphasises the need for clinicians and practitioners to recognise the ever-shifting needs of sufferers of chronic illness and to avoid assuming that chronic illnesses run linear courses. As the symptoms of a condition ebb and flow, the foregrounding of illness or wellness will have specific functions and effects on self. Paterson explains that when wellness is in the foreground, the self, not the diseased body, is the source of identity and that the body is objectified. This alters the relationship between mind and body so that the body is experienced separately from mind. There is also an issue that concerns how the agency of the sufferer is viewed, which is about the apparently passive way that the self responds to an ill body, rather than reflecting a unity with the body.

However, Cohn (1999) suggests that the issue of mind-body dualism in ME is less about aetiology and more about personal control and that the dualism remains a useful device for assigning boundaries, culpability and moral responsibility. For this reason it is possible that the issue of mind-body dualism in ME is an intractable ontological issue. The implication for this thesis is to consider how ME might transcend characterisation as psychological, social or physiological and where and how self can be thought about within this arrangement. Nevertheless, it is important to recognise that the variable course of illnesses affects how the relationship between self and body is understood.

A further implication for this thesis is that the human body is predestined to interact with, manipulate and change objects in the external world. Hence a necessary relationship between self, body and external object is implied. Relations with external objects also provide a sense of boundedness and help constitute external reality (Mead, 1934). However, objects affect us in ways linked to their own specific nature and potential use (Bollas, 1987). In this sense they oblige themselves upon us and afford certain actions. The implication is that the self arises through dynamic interaction of the body *and* material objects (McCarthy, 1984). Thus, to make sense of the social and relational aspects of self involves making sense of the part played by non-human objects because these form part of the semiotic system through which self is constituted.

In this section I have outlined the complex relationship between chronic illness and the self as a means of moving towards the model of self I intend to work with. My route into this discussion was to highlight the importance of qualitative social scientific health research and the manner in which it complements biomedical research by exploring and representing the experiences of ME sufferers. I described the ways in which illness symptoms are experienced reflect their interaction with social context, mind and body. Because illnesses such as ME run unpredictable courses and disrupt the unity of mind and body, ME sufferers are obliged to reassess self and self-development as an ongoing dynamic process and this points to the contingency of self which I outlined in relation to poststructuralist notions of subjectivity and discourse. Finally, I briefly outlined the importance of situating the self and body in a material context, given that making sense of the social and relational aspects of self necessitates making sense of the part played by the non-human objects which act as ‘signs of the

self” (Rochberg-Halton, 1984) and through which, in conjunction with the body, the self arises.

3.3 Review of qualitative social scientific research on the relationship between ME and self

In the previous section I discussed ME in the context of general social scientific research into health to provide a backdrop to some of the issues involved in thinking about how an illness such as ME relates to the self. The present section represents a review of empirical work that has addressed the relationship between self and ME directly. My aim is to not only represent the broad range of approaches by which ME has been explored but also to provide a sense of the variability of ME experience and that the manner in which it is understood reflects underlying epistemologies.

Many studies chart the trajectories of how illness affects the self in ME. For instance, Clarke and James (2003) describe two modes of identity construction following ME. These are immediate and total loss of identity marked by separation from existing activities and friends and then the development of a *radical* self that was better than the previous one and involved rejection of the values of the old self. They did not find a desire to return to the former self, nor the creation of a new improved or *supernormal* self. Whitehead (2006) found that across a two and a half year period different priorities were set and that identity became progressively more positive as ME progressed. The trajectory reflected Clarke & James’ work that identities were pendular and could move backwards to a past identity and forwards to a new identity with the time period dependent on illness severity and its impact. However, Whitehead did not support findings by Charmaz (1983) that identity became progressively worse and that sufferers of chronic illness adopted restricted lives. Nor did she support Asbring’s (2001) findings of a partial identity disruption. As noted by Clarke and James (2003), these varied findings may reflect differences in sample types, the degree of systematicity of analysis or research questions.

Interpretative phenomenological analysis (IPA) has been employed to explore the effects of ME on self. The aim of IPA is to investigate the processes through which participants make sense of experiences (Chapman & Smith, 2002; Dickson, 2004; Brocki & Wearden, 2006) by focussing on their understandings, perceptions and views as a whole (Moustakas, 1994; Reid, Flowers, & Larkin, 2005). This is a phenomenological perspective because the focus is on the conscious perception of

phenomena in an individual's world as they engage with it and how their private conscious experience is implicated in their accounts (Dickson, 2004).

IPA studies support findings that ME sufferers experience a delegitimisation of their conditions due to a lack of definite organic aetiology, often exacerbated by physicians' scepticism and lack of knowledge about the condition (Dickson, Knussen and Flowers, 2007). Delegitimisation exacerbates the identity crisis that sufferer's experience (Dickson, Knussen & Flowers, 2008; Arroll & Howard, 2013). This identity crisis is described as not only a loss of self but in some cases also as a loss of embodiment, implying the impact ME has and how it fragments the unity of self and body.

ME affects the self on an everyday basis as well as across the life trajectory. Arroll, Dancey and Attree (2010) used IPA and found that sufferers begin their days with numerous worries centred on their ability to carry out daily tasks, strategies for scheduling activities and comparisons of present health with pre-morbid health. The implication is that ME exacerbates the worries that people may normally have. Arroll & Howard (2013) found that ME sufferers were obliged to redefine their sense of self due to the physical limitations imposed by ME. The authors state that their findings support Charmaz's (1983, 2000) that former self-images could diminish whilst more positive ones formed. However, and perhaps typical of IPA studies on ME, a specific conceptualisation of self is not explicit. Where this is discussed it is usually couched in terms that participants use, which is useful in attempting to stay with participant descriptions but less useful if the term 'self' is to be used in a more explanatory manner. However, IPA puts self firmly in a spatial and bodily relationship and this is important.

Given the subjective experience of self and the ubiquity of the interview method and listening to peoples' narratives, one specific means of thinking about illness and self is in terms of *biographical disruption* (Bury, 1982; Asbring, 2001). This is where the autobiographical narrative of one's past, present and future is altered in light of the effects of illness. Corbin and Strauss (1987) claim that this narrative work focuses on the construction and maintenance of a self that is the same as before the illness or one that is better. Narrative analyses of ME patients' talk suggest that ME sufferers often struggle to make sense of the condition due to its remitting-relapsing, unpredictable course (Ware, 1999; Horton-Salway, 2001; Whitehead, 2006). As such, a biographical understanding implies the temporality of self experience.

Bury (1982) asserts that illness disrupts future-planning and marks a biographical shift from a perceived normal trajectory to one that is unpredictable and damaging. Bury's work with arthritis sufferers is useful in drawing attention to how illness-onset disrupts everyday material practices as well as the capacity to make meaningful sense of things and a new awareness of the contingency of body. Charmaz (1987) states that managing chronic illness involves making sense of the changes to expected life trajectories and re-establishing order in light of their disruption. This implies that chronic illness is invariably a negative experience and involves the loss of previous, better identities and sense of self.

In contrast, Carricaburu and Pierret (1995) note that in some instances, such as with the elderly or those affected by illness from birth, chronic illness may be understood as part of an ongoing biographical arrangement rather than as a rupture from a previous self. Also, Asbring (2001) in her interview-based study of 25 Swedish women suffering ME or fibromyalgia concludes that identity transformations associated with biographical disruption may be partial and involve positive gains as well as losses, such as re-evaluation of habits and attitudes leading to positive behavioural changes.

However, Williams (2000) points out that the notion of biographical disruption, whilst useful as a reference point in the sociology of chronic illness, needs to be situated against changing conceptualisations of pain, suffering and self in the postmodern era. This is most pertinent in terms of how contemporary neoliberal health discourses lead to the signification of pain and its relationship to the body in specific ways. As Karfakis (2013; p.5) notes:

“The human body is a field of conflict between different discourses such as the law, biomedicine, and economics, and each one of them promotes a different subject.”

Implied is the need to acknowledge the contingent nature of any claims that can be made about how ME affects the self and how self is conceptualised in relation to the body.

Discourse analysis (DA) has been especially influential in exploring the experience of ME and represents a range of approaches focussing on the way that people construct meaning through language (Willig, 2001). Language is understood as functional in that people use descriptions to perform actions (Langridge & Ahern 2003). DA assumes that language is neither a direct correlate of inner experience nor a neutral account of

the world and cannot be assessed for truth. In this sense, DA challenges the assumptions of cognitivism that attributions about illness correlate with beliefs and behavioural changes (Potter & Wetherell, 1987).³ Instead, descriptions are constructed to anticipate and mitigate against scepticism (Horton-Salway, 1998, 2001). DA therefore contrasts with other qualitative approaches in that its focus is how meaning is constructed through language, rather than to understand the meanings that phenomena hold for people (Dickson, 2004).

DA has shed light on several aspects of the ME debate. For instance, it is commonly reported that ME is over represented by white females. However, feminist critiques of the Western construction of illness highlight the gendered nature of ME and its overlap with cultural expectations of female social roles; where ME was constructed as an escape from the burden of conflicted identities and responsibilities (Richman, Jason, Taylor and Jahn, 2000).

Against this backdrop, Hart and Grace (2000) used DA to investigate women's narratives on fatigue. A discursive field emerged in terms of energy as a mechanical flow and blockages. The implication is that if fatigue and energy are understood in metaphorical terms then they are not biomedically representable. This means that, biomedically, fatigue is studied piecemeal and the complexity of this symptom is missed. Moreover, fatigue challenges the notion of body as object and the self as subject because the sufferer moves between adopting a position where the body is opposed to the self and a subjectifying stance where the body is the self. This complicates unravelling the objectivity of ME symptoms such as fatigue from their subjective experience.

An important focus of DA has been the delegitimisation of ME. ME sufferers are often stigmatised by the condition due to lack of positive diagnosis and aetiology (Asbring & Narvanen, 2002; Looper & Kirmayer, 2004). Obtaining a diagnosis is a struggle (Arroll & Senior, 2008). Tucker (2004) states sufferers manage this effect of ME on self-identity by adopting certain discursive positions in relation to debates around the illness. Because no single discourse can satisfactorily represent ME, competing discourses exist, resulting in scepticism concerning how sufferers are perceived; as is the case when the condition is attributed a psychological aetiology. Tucker demonstrates how sufferers attempt to mitigate this effect by establishing a discourse

³ See chapter 2; 2.9.

of ME as an organically based and consequently legitimate illness. This work supports findings by Clement, Sharpe, Simkin, Borrill and Hawton (1997), Horton-Salway (2002, 2004, 2007), Asbring & Narvanen, (2002, 2003), Clarke & James, 2003, Raine et al. (2004) and Soderlund & Malterud (2005). However, Asbring and Narvanen (2004) demonstrated that by gathering knowledge of the condition, sufferers can make demands of health providers to avoid or gain access to certain health options by using strategies such as non-compliance, distancing and persuasion. This connotes the active processes involved in identity management and that sufferers are not merely in a passive, powerless position.

Overall, from the discursive perspective, identity and how ME affects self experience involves the management of alternative or competing attributions. These alternative attributions involve the specific interactional situation, the specific nature of the illness and what is at stake. If sufferers accounts of ME are taken at face value, attributions of personality type might be made that are taken up by biomedical discourse as justification for treatment approaches (Guise, Widdicombe and McKinlay, 2007). If ME sufferers attribute their condition as very serious, irrespective of definite clinical signs, this is easily psychologised as a cognitive bias that justifies the use of CBT.⁴

Illness identities are thus constructed in situ. This is in contrast to perspectives that adopt an essentialist model of identity (Horton-Salway, 2001). However, whilst DA has been useful for shedding light on the construction and management of ME 'identities' in relation to cultural discourses, an issue with discursive approaches is where to draw ontological distinctions between material and discursive practices (Wetherell, 2001). If a Foucauldian framework is adopted, where 'discourse' refers to a group of historically and culturally specific statements that provide a language through which specific knowledge can be represented, then no distinction can be made between material practices, including the nature of the body, and a discursive understanding of them (Hall, 1997). This arguably diminishes the capacity for an autonomous self and particularly the subjective experience of ME from the sufferer's perspective. It is thus apposite to reconsider the relation between self and materiality.

What can be taken forward? Whilst qualitative work suggests that ME results in various trajectories of identity reconstruction, an approach that focuses on each *particular* experience of ME would reveal how that variability is related to specific life

⁴ See chapter 2; 2.9.

experience, antecedents and specific material environments. To date, qualitative work on ME has relied largely on the interview method and this has been useful for enabling sufferers to narrate their history as they understand it. However, to capture a broader slice of the trajectory of ME and how it affects self it would be beneficial to develop ethnographic, longitudinal methods that enable the researcher to enter into the everyday experiences of the sufferer. This is important given qualitative work revealing that the everyday management of ME necessitates that sufferers develop coping methods and causes them daily concerns.

How self and body are related to ME results in various trajectories of effect on identity and self experience. These appear to reflect not only research methodologies but also the specific balance between illness and wellness. The body becomes a site on which the ME debate is inscribed and contested and which has repercussions for how the body is experienced. However, from poststructuralist perspectives, the discursively produced body does not easily lend itself to scientific scrutiny and this destabilises biomedical science's ability to categorise the body in an absolute sense. From this perspective, the sufferer struggles to know their body with certainty, suggesting that how self and ME are experienced is mediated by social context and its relation to the body.

The focus of phenomenological experience shifts between the body and self depending on whether the body is functioning normally or not. When the body is functioning abnormally, it is experienced in a more objective way and this implies that the relationship between self and body can be viewed along a continuum with differentiation of the two at one end and their unification at the other. This alludes to a dynamic relation between body as object and body as subject and hence the self. To take this forward, the body in my thesis is conceptualised as a site reciprocally engaged with subjective experience. The body is coincident with social and cultural discourses and these in turn reflect specific material contexts. One focus is consequently on the associations or the *relationality* of the body. Beyond the mind-body problem, ME is often experienced by sufferers as confusing and inexplicable (Robinson, 2003; Dickson, Knussen and Flowers, 2008) and this provides a further avenue of exploration.

The model of self I intend to develop in this thesis is therefore non-essentialist and reflects a fluid contingency of self that accommodates shifting social cultural

discourses and the ever-changing material contexts of the world. But given the subjective experience of self as stable and continuous (James, 1890) I also seek to maintain some interiority of self that reflects a sense of stability and autonomy. However, I am not positing a dualistic split between self as fluid and self as stable, nor between an absolute interiority of self. Instead, the emphasis is on relationality, such that at any given time how self is experienced depends on the way in which the body, materiality, discourse and the extra-discursive coalesce.

To this end, the subsequent section presents an overview of ‘psychosocial approaches’. This is an area infused with ideas from disparate fields of thought and which represents a flexible, eclectic mix of methods and theories that provide a suitable framework from which to consider the effect of ME on self experience. A psychosocial approach frames this thesis because it enables a reconceptualisation of the boundaries between inner and outer, mind and body and acknowledges the particular yet social nature of ME.

3.4 Psychosocial approaches: framing ME

The term ‘psychosocial’ covers a varied range of research approaches and indicates a shift of emphasis away from dualistic thinking to questions of subjectivity and the forces that shape it (Clarke & Hoggett, 2009). Lucey, Melody and Walkerdine (2005) argue that to get beyond conscious and rational explanations of people’s behaviour requires a greater understanding of how the psychic and social processes that influence behaviour come about. A psychosocial approach represents a critical stance that challenges the notion of the ‘rational and autonomous human’ that has characterised social understanding and policy since the Enlightenment (Frost & Hoggett, 2008). Bracketing off rational epistemology and methods is crucial so that the confused and contested aspects of ME can be explored.

This heterogenous psychosocial field draws on feminist, anthropological, post-structuralist, discursive and psychoanalytic bodies of theory and research as well as continental philosophy (Clarke & Hoggett, 2009). It enables interdisciplinary non-rationalist, non-reductionist means of conceptualising the connections between body, psyche and society and advocates methodological and theoretical pluralism (Frosh, 2003). In this vein, psychosocial approaches are highly concerned with the philosophical underpinnings to the theories they call upon. For instance, the work of the French philosophers Deleuze and Guattari and their re-envisioning of bodies,

desire, spaces and relationships has been influential across disparate areas of psychosocial study from education to social justice (Zembylas, 2007; Manley, 2010; Henriques, 2010; Walkerdine, 2013). Influences such as this enable the psychosocial field to stand outside of positivist psychology and adopt a critical stance.

The psychosocial field is fundamentally concerned with subjects and subjectivity and provides critical analyses of the tensions between external social and internal psychic formations (Frosh & Baraitser, 2008). Most importantly, psychosocial approaches recognise that the dichotomies of individual-social and psychology-sociology are unhelpful to studies in these areas (Clarke & Hoggett, 2009) and enable a reflexive account of the research process.

The application of psychosocial approaches and thinking is extremely broad and this eclecticism lends it to the study of ME. Studies include the exploration of young masculinities (Frosh, Phoenix and Pattman, 2003), film analysis (Froggett & Hollway, 2010), the effect of macro political and organisational influences on cross-organisational relations in a local authority (Watts, 2009), social policy and gender (Chamberlayne, Rustin & Wengraf, 2002; Hunter, 2009; Crowhurst et al. 2011), the experiences of ethnic groups in education (Clarke, 2002), a reconsideration of sibling relationships and their effects across different contexts (Edwards, Hadfield, Lucey and Mauthner, 2006; Gillies & Lucey, 2006; Young & Frosh, 2010; Lucey, 2011), understanding embodiment and gendered relationships (Frost, 2005; Featherstone, 2010), the relationships between education, class and gender (Frosh, Phoenix and Pattman, 2003; Walkerdine, Lucey, Melody, 2001; Walkerdine, 2013) and the exploration of experiences involving shame, suffering, embarrassment, loss and hurt (Frosh & Hoggett, 2008; Jimenez & Walkerdine, 2011).

Its flexible and innovative nature renders a psychosocial approach appropriate for the present thesis. The emphasis on thinking about how the “out-there” gets ‘in-here’ and vice versa (Frosh and Baraitser, 2008) is key. Put another way, psychosocial thinking attempts to collapse binaries such as social-individual, inner-outer and mind-body and instead thinks about the processes, relationships and experiences that mark them in non-dualistic ways. Sociological work that has considered the relationship between the individual and society has been limited by an unwillingness or inability to work with notions of unconscious processes (Lucey, Melody and Walkerdine, 2003). In this vein, the work of Lucey et al was amongst the first to challenge the notion that

social class was only a structural, social category. By exploring the interrelationship between class and the psyche, Lucey et al demonstrated that what might otherwise be taken as outcomes such as the educational success or failure of girls education ascribed to class, were in fact the result of a [psychosocial] relationship between class *and* unconscious processes. Thus, a psychoanalytically informed psychosocial approach posits subjectivity founded on the unconscious ways that the social becomes imbued with the psychic and vice versa. The psychosocial is consequently a meeting point of inner and outer forces and is constructed as well as constructing (Frosh, 2003). Moreover,

Approaching ME from a psychosocial perspective encourages the conceptualisation of imaginative ways of bringing together the disparate elements of ME experience. For instance, a discursive approach might explore the constructed legitimacy of the condition but is perhaps less focussed on how the condition feels. Moreover, a psychosocial approach suggests that the discursive sense that is made of ME is easily undermined and hence experienced in conflicted ways, given the role played by the unconscious wishes and obstacles that are always already an implicit part of the experience of ME as expressed through language. Also, phenomenological approaches may bracket off the reality of entities such as viruses and focus on the subjective reality of the experience but not the material reality of the entities involved. Thinking psychosocially provides a way of enhancing sociological explanations of ME that at the same time acknowledges the importance of material entities such as viruses and environments.

As the focus of this research is the experience of ME and its effect on self, a psychosocial framework is fitting because its non-reductive stance encourages the exploration of the relationship between the self and body and their construction in reference to ongoing relations and experiences in a material world. This relationship is important because the embodied self resides in a world where it has to respond to the mediating effects of material and social demands and restrictions (Millward & Kelly, 2003). Given the relationship between the self and body and their construction in reference to ongoing experiences in a material world, emerging psychosocial approaches are ideally suited to reconsider the complex entanglement of self with culture. For example, at the heart of Jones' (2013) analysis of the looting and riots in the UK in 2011 are the relations between materiality, consumer culture, masculinity and criminality.

Jones interrogates the cultural turn in criminology and draws on different strands of psychoanalytic theory to argue that culture must be understood as partly constructed 'by and within' the internal worlds of the individuals that culture is already comprised of. And yet this already complex arrangement also implies more fundamental differences between the genders that help explain why men are more disposed to the pitfalls of [consumer] culture in the first place.

Given the great potential for feelings such as shame and guilt with regards to criminal acts and the losses and gains of being part of a social world, maintaining the self inevitably involves an enormous amount of reparative psychological work (Lucey, Melody and Walkerdine, 2003). As Frosh (1991) notes, the self involves an ongoing struggle of construction and maintenance and the expenditure of considerable psychological energy. This implies the contingent nature of the self, which can be understood as the meeting place where the social and physiological effects of ME are experienced. A psychosocial stance is useful because self can be thought about in terms of the dynamic relationships, or process, involving various social, physiological and psychological entities.

A psychosocial approach can be developed which extends the conceptualisation of self to incorporate the materiality of the environment and objects because, as Frosh (2003; p.1547) puts it, the psychosocial is a space where elements such as:

“...‘individual’ and ‘society’ are instead thought of together, as intimately connected or possibly even the same thing.”

A psychosocial view of self can utilise and enhance a discursive understanding [of ME] (Frosh, Phoenix and Pattman, 2003). Parallels can be drawn for example between ME and Foucauldian inspired discursive understandings of how feminine identity and the feminine body is policed and constructed through technologies demonstrative of gendered power regimes (Davis, 1995; Frost, 2005). Just as these involve the reconciliation of the body and identity with gendered social discourses that view the female body as requiring transformative 'improvements', ME involves discourses structured through power that delegitimise ME and a body that is felt and viewed as inadequate (Horton-Salway, 2001; 2004; Tucker, 2004). Both the ME sufferer and women “are caught up with processes of normalisation and homogenisation” (Lovell, 2000; p.341).

Considering the self as psychosocial provides a means of developing a ‘thick’ description [of ME] (Braun & Clarke, 2006). Psychoanalysis is central to the strand of psychosocial thinking drawn on because it provides a way of thickening interpretation of personal narrative by calling upon sophisticated ideas about emotional investment, phantasy and unconscious processes (Frosh & Baraitser, 2008). From this perspective, understanding people’s practices and social realities involves exploring their fantasies about relations and subjective ideas (Froggett & Hollway, 2010). This stance enables consideration of the temporal aspects of subjectivity and self experience because, from the psychoanalytic perspective, interactions in the present contain symbolised interactions from the past. These interactions are comprised of cultural, idiosyncratic and personal patterns of relating and how these are embodied materially. Interaction therefore transcends the inner and the outer worlds (Froggett & Hollway, 2010).

In terms of understanding the anxiety that ME causes, a psychoanalytically informed psychosocial stance is also useful. Anxiety necessitates the mobilisation of defences which are both psychically and physiologically experienced. But they are also socio-culturally mediated and produced and experienced individually. This is why they need to be understood as ‘psychosocial’ (Lucey, Melody and Walkerdine, 2003; Froggett & Hollway, 2010).⁵ However, a difficulty for psychoanalytically informed psychosocial approaches has been to develop a version of the unconscious that is not reduced to an individual, internal process (Froggett & Hollway, 2010). This reflects an ontological concern that psychoanalysis posits an unconscious ‘reality’ that stands behind the individual in a determinant manner and which can be excavated using specific psychoanalytic concepts and tools. However, this is a misunderstanding of psychosocial approaches.

The appeal of a psychosocially framed recourse to psychoanalytic ideas is that there exists a productive tension between what appear to be opposed versions of psychoanalysis. This tension encourages the development of imaginative thinking and methodologies, such as a more materialist treatment of society and culture (Froggett & Hollway, 2010). Thus, rather than trying to find some underlying reality that directly correlates with what is assumed as the ‘truth’, the task of the psychosocial researcher is to understand the dynamic interplay between elements, such as ME symptoms,

⁵ Some researchers in the psychosocial field are wary of psychoanalysis because of its individualising tendency, its appearance as expert “top-down” knowledge and its apparent claims to know more about the truth of an individual than the individual themselves (Hook, 2008).

discourse, viruses, self-understanding and material environments, all of which comprise the experience of ME. My focus is consequently on relations and process and how the effect of ME on self can be understood in relational terms. Adopting this relational perspective provides a place from which to understand how disparate elements come together and how self experience implicates the material world.

In summary, thinking about ME psychosocially encourages developing an understanding that challenges notions of the self as rational and autonomous. Acknowledging the confusing character of ME and the unconscious ways that its social aspects become imbued with the psychic and vice versa enables a thicker description of how the condition is experienced. A psychosocial approach encourages thinking about how disparate elements, including materiality, come together in ways that do not reduce self to either a social nor individual matter. From this perspective, thinking about self and how it is affected by ME enables an appreciation of how different sufferers can have similar yet different experiences of the condition. I refer to this as the *particularity* of ME experience; drawing attention to how each sufferer exists in different material environments, engages in different activities and is exposed to different life events and people.

As discussed, a significant influence behind psychosocial approaches has been psychoanalytic perspectives. Such perspectives are useful when thinking about self because they enable an exploration of the relationship between mind and body as well as seeking ways of understanding the contradictory, confused and less than transparent aspects of individual and societal phenomena (Clarke, 2002). In the subsequent section I discuss how inspiration can be gleaned from specific psychoanalytic theories to inform a non-dualistic, non-reductive understanding of ME and its effect on self experience. I outline key ideas from Sigmund Freud, Melanie Klein, Donald Winnicott and Robert Stolorow and George Atwood and describe their relevance to this thesis.

3.5 Psychoanalytic perspectives and developing a ‘psychoanalytic sensibility’

Psychoanalytic ideas enable the conceptualisation of the unconscious and confusing aspects of behaviour and experience as well as providing a means of re-articulating the mind-body dualism which characterises ME. Specifically, psychoanalytic theory addresses what happens at the interface between body and mind and self and object (Elisha, 2011) and represents a move away from the notion of a coherent and

continuous inner self, positing instead a self split between conscious and unconscious aspects (Frosh, 2002). The appeal of psychoanalytic ideas is that they retain tension between a dynamic self divided by unconscious conflict and innate anxiety and a self that has a core ego that is largely constructed through identification and the internalisation of objects from birth and likely before; an ego more resistant to change and defies fluidity. It is this epistemological perspective on self, one where the self is comprised of internalised others in dynamic, relational ways that reflect change and stasis, which is appealing.

3.5.1 *The work of Melanie Klein*

The relationality of self is reflected in the work of Melanie Klein (1930; 1944; 1945; 1948; 1953; 1957; 1975; Klein & Riviere, 1967; Mitchell, 1986) and is important because it enables thinking about peoples' relations to others, material objects and their relevance to development of the self in terms of how objects become internally represented in the mind.

Klein understands self as inherently relational in that the first point of contact with the world is the body of the infant, who experiences first one body-part then another as libidinous, instinctual drives are directed to various places such as the mouth and anus (Klein, 1986). Klein explored how psyche and soma develop in conjunction with the external world and shares common ground with Freud in asserting that the ego is primarily a 'bodily ego' (Freud, 1923)⁶. This is an important notion because it necessitates that the body is brought into the analysis of, and is inseparable from self, reflecting the non-dualistic approach to self advocated in this thesis.

For Freud, the body informed psychic development via instincts whereas Klein's pre-existent ego represents a metapsychological entity that apparently precedes and ultimately prioritises the psyche over the body (Elisha, 2011). This represents a move from a causal explanation of psychic development to a teleological one because the unfolding of a pre-existent ego implies that psychic and hence bodily developments are

⁶ This represented Freud's attempts to conceptualise a framework free of the mind-body dichotomy (Pollak, 2009). The ego and its developmental path represent the fundamental difference between Freud and Klein. For Freud, ego appears within the first year of existence, whereas the Kleinian ego, responsible for integrating aspects of the unconscious and conscious self, appears in elementary form from birth (Klein, 1959). This puts the relationship between mind and body in a different ontological perspective because of the way that 'being' from the outset fundamentally involves the ego or not.

shaped in a pre-determined way (Chessick, 1980). However, whilst Klein's relational model of the psyche is not biologically reductionist like Freud's it does not address the mind-body dualism in a way where the external world is maintained as an ongoing significant relation (Elisha, 2011). This appears to diminish the importance of the external, material world and it is partly this that I address through this thesis.

Despite Klein agreeing that the ego is primarily a body-ego there appears to be an ontological incompatibility, or at least a lack of explanatory clarity. The problem is that a pre-existent metapsychological construct [ego] is being called upon to explain the appearance of further mental constructs without actually explaining the connection to somatic processes. This reflects an explanatory gap between mind and body and which in itself points to the need to be creative and non-dogmatic with theory. Ultimately, Klein's prioritisation is of the mental over the somatic, which reprises the mind-body dualism. Pollak (2009) states that the body cannot and should not be subordinate to its representation via mental constructs which focus on transforming somatic states to symbolic representations.⁷ It is here that a psychosocial stance is useful because it emphasises how the self is constructed through processes of identification with the external world, given the:

“...flow and interchange between inside and outside; the ways in which we dynamically take on aspects of the outside world, and also how parts of ourselves are experienced as existing out there, in other people and objects.”
(Lucey, Osvold and Aarseth, 2013; p.7)

My objective is to therefore to think about the self in terms of a material world that has an ongoing effect on how self is experienced and understood without reducing self to body or body to materiality. This is important because ME clearly affects sufferers' ability to engage with a material world as they might have done prior to ME. However, psychoanalytic ideas provide a means of creatively exploring the ways that self, body and material objects are interrelated as well as lending themselves to extension and enlargement. This is part of the psychoanalytic sensibility I seek to develop.

For example, at the interface between the psychological world of the individual and the outer world is Klein's notion of *phantasy* (Isaacs, 1948; Mitchell, 1986).⁸ Phantasy, spelt 'ph' to distinguish it from conscious fantasy, represents primary and innate

⁷ See Freud (1923; 1933); Isaacs (1948); Hinshelwood (1991).

⁸ See Klein (1946; 1957) and Isaacs (1948) for a discussion of *object relations* and how the infant begins to build up symbolic, internalised phantasised versions of the external world and others initially via it's relation to *part-objects* such as the mothers breast.

unconscious representations of instincts, which link objects to feelings, (Freud, 1915; Isaacs, 1943; Money-Kyrle, 1957). Kleinian psychoanalysts view the unconscious as comprised of phantasised relations with objects. Phantasy is a bodily-framed language in which body parts stand in for weapons or presents, such that a baby feels suckling milk as love (Segal, 1957). When the capacity for symbolisation has developed, feelings can be expressed in words. Phantasy implies that neither the body nor the external world can be perceived directly. When the capacity for symbolisation has developed, feelings can be expressed in words. Indeed a psychoanalytic interpretation of ME might view ME as the failure to integrate or deintegrate experience and the manner in which it leads to undifferentiated internal states. Driver (2005) describes the experience of ME as unprocessed unconscious material that becomes conflated with anxiety and psychological defences. Part of this is the difficulty in separating out reality from phantasy. For example in how the patient in Driver's clinical analysis of ME reprised the anxiety associated with her lack of a maternal figure that was able to process her experiences as an infant. This ME sufferer obsessively defended against anxiety and bodily experience as an adult, through over-functioning and obsessively attacking her body with over or under activity; features of ME. This patient's psychological experience of ME became one which:

“...embodied and symbolized the internal hurt child with the internalized helpless mother who could not engage with the child's experience or process and understand it.” (*ibid.* p.158)

This is already a useful interpretation of ME because of the way in which it highlights how unconscious processes of phantasy mediate the manner in which body and self is experienced [in destructive ways]. On the other hand, such an interpretation appears to pay too much attention to the internal world of the sufferer and its roots in childhood. In contrast, it is equally important to account for ongoing dynamic relations to the external world, as I aim to demonstrate.

Nonetheless, phantasy implies that neither the body nor the external world can be perceived directly. This is not only important in exploring the reality created by sufferers of ME, but also as part of the process of exploration on the part of the researcher. For example, Froggett and Hollway (2010) claim that whilst it is relatively easy for social scientists to account for their understanding of social processes, it is more difficult to account for the quality of this understanding because it draws on on

the researcher's unconscious awareness and the manner in which this awareness is 'impelled' by phantasy.

The value of ideas such as phantasy is that they provide a means of describing how experience is often mediated in ways that occur beyond conscious reflection and may appear contradictory or at best confused, as well as providing a language to explore the connections between mind and body. Such a perspective entails that searching for simplistic causal relations between things and rational explanations of experience and behaviour might be better addressed by exploring the relationality of mind, body and the world in terms of coextensive, non-causal associations. In other words a view where self and body and the material world and others are coincidental rather than related in a simplistic causal sense.

The issue is how to conceptualise mind and body in a non-dualistic manner without prioritising one over the other and hence in ontologically different registers. Despite concerns with Kleinian ideas, for instance the way that the real external object appears to be less important than its internalised mental representation, they open up a space from which to begin thinking about how the psyche and hence the self meets the external world, others and objects (Young, 2011). It is also important with regards to ME because of the contested relationship between mind and body, the conflated nature of symptoms and the largely unexplored relationship between ME and the external material world of objects and places. These ideas provide a template of the dynamic nature of the self and the interplay between the many aspects and entities that comprise ME. For instance in how the materiality of a virus and its physiological effects are also symbolically mediated through unconscious processes, resulting in elements of experience that are not immediately available for conscious interpretation.

3.5.2 *The work of Donald Winnicott*

The relationship between the inner world of the psyche and the external world was carried forward and developed by subsequent psychoanalytic theorists such as Donald Winnicott. Winnicott is important because he informs thinking about how self forms not as a teleological unfolding of a pre-existent ego, but as an emerging in the space between the inner and outer worlds and their ongoing reciprocal relations. He provides a starting point from which to focus on the materiality of external objects.

Like Klein, Winnicott was influential in the Object Relations school of psychoanalysis, theory and clinical practice; a field that focuses on how the psyche develops in relation to others and how these others are internalised as objects. From the outset, Winnicott emphasises the ongoing environment and its effects (Gomez, 1997). Whilst Klein was more concerned with the subjective experience of the life and death instincts, Winnicott was more concerned with the infants' adaptation to reality in relation to the quality of maternal care. This implies the social nature of the psyche by demonstrating that a baby never exists in isolation but is immediately in the care of an adult (Winnicott, 1952). He understood that the infant's self could not develop unless it managed to differentiate itself from the mother whilst somehow remaining in touch with this objective source (Davar, 2001; Winnicott, 1965).

Winnicott thought of the immediate environment of the infant as a *transitional space*, inscribed by the subjective experience of the mother/infant dyad and the real breast. This notion describes metaphorically how social and psychological modes of experience intersect and where meaning is created and re-created to produce a sense of self and cultural experience (Winnicott, 1965; 1971). The significance of what happens in this space depends on the mother's behaviour and how the self emerges from an unintegrated complex of somatic feelings (Winnicott, 1954). It is through this space that the developing self learns the capacity to symbolise and in doing so distinguishes what is 'me' from 'not me' and becomes differentiated. The concept is important for this thesis because the implication is that the self is a developmental achievement, reflecting fundamental relations with others and an external world reconciled as part of the self in ways that are particular to the individual. This also implies the dynamic, ongoing developmental nature of self.

Development of what is 'me' and 'not me' may occur via a *transitional object* (TO). This is the first 'not-me' object and is often something the infant adopts, such as a soft corner of blanket, a piece of wool or a cuddly toy (Winnicott, 1971). The TO symbolises real part-objects such as the breast but its own materiality is as important as its symbolic value. This concept provides a way of talking about how the inner and outer world is bridged by incorporating materiality itself. It implies not the unfolding of the psyche in the teleological sense of Klein and the negation of the real external object, but development comprising of the ongoing presence and behaviour of real objects and the maternal environment in an imaginative way. Winnicott (1953) viewed the earliest transitional phenomena and objects as rooted in bodily experiences, for

example between the infants' thumb and the TO, which collapses the mind/body dualism into an intermediate transitional space. Moreover, the TO functions as a means to overcome unconscious anxiety and in the normal course of development the infant learns to exteriorise symbolically and differentiate itself from the outer world.

The notions of transitional spaces and objects lend themselves to creative exploration of the relationship between self, body and places and objects as part of our ongoing project of self. Chittenden (2013), for instance, provides an illuminating discussion of the relationships between the transitional space provided by an arts degree course and transitional objects such as the paintings produced by a female student who struggled to reconcile her own body shape and female body image with the norm of contemporary culture or historical artwork. In Chittenden's analysis, an arts degree course provided a frame for the student to play with different roles and practices as well as the possible enactment of different desires and identities. Through this space, the student developed creative strategies with which she could explore her sexual desirability and aesthetic self. The paintings themselves represent objects through which her identity was shaped and could eventually emerge as part of the process of negotiation which also involved critical reflection and verbal discussion of the work. What is important about this study is that it demonstrates how self development implies sociocultural and individual processes intersecting with material objects and practices.

Thus, thinking about the space between inner and outer worlds and between self and other and how these relate symbolically to the wider cultural field leads to a consideration of the relational nature of objects and self. This is a focus on the relations between things rather than the things themselves; a perspective that eschews causal arrangements where one thing is causally related to another in favour of envisioning a space where various developmental threads coalesce and associate with each other in coincident, productive and imaginative ways. Conceptualising this metaphorical space provides a rudimentary model of thinking about how seemingly disparate and ontologically incompatible things come together. However, as implied by the work of Klein and Winnicott, the real other is in one way or another present as part of the self and for this reason it is important to reconcile the aspects of self-development discussed thus far with ways of thinking about what occurs when the real other is engaged. This involves thinking about relations with others as neither internal nor external but in terms of an intersubjective space between and around people.

A relatively recent development of psychoanalysis that addresses the relations between people is Stolorow and Atwood's (1992) concept of intersubjectivity, which reflects a move away from the notion of the individual isolated mind of early psychoanalytic models towards the contextualised, mutually influencing interaction of subjectivities (Stolorow, Brandchaft, & Atwood, 1987; Mitchell & Black, 1995). Intersubjectivity theory also represents a move away from either/or questions about the dual or monistic nature of psyche and soma and places the body at the junction between subjective experience and its relationship with the outside world (Elisha, 2011).

As Benjamin (2005) notes, the importance of intersubjectivity theory is not only in addressing the subject-object problem but also to shed light on the process of the mutual engagement and recognition occurring between people. Mills (2005) observes that from the intersubjective perspective, affective attunement, social construction, and mutual recognition takes precedence over the role of interpretation. This stance resonates with my aims because what this thesis attempts is to comment on the experience of ME and self but not to provide an explanation of them.

Stolorow and Atwood's notion of intersubjectivity takes as its departure-point two interacting subjectivities that form an intermediate relational space (Thompson, 2005). In other words, how self is experienced and how the other is internalised occurs in between people, rather than in terms of two separate selves as might be implied by the notion of the isolated mind inferred by classical psychoanalysis. Stolorow and Atwood suggest that establishing mind as distinct from the body produces the illusion of a self free from the constraints of biological bodily rhythms, the wider physical environment, others and mortality. This serves as a defence against physical vulnerability but necessitates the reification of spatial, temporal and substantial aspects of subjectivity. Stolorow and Atwood contend that this reifying process involves constructing the world as 'real' and separate from the self. In terms of self, this points back to the over-valuation of the autonomy necessary for a model of self that rests on the isolated-mind myth (Elisha, 2011).

Conceptually, it is important to retain the tension between the subjectively experienced body and intersubjectivity. Elisha (2011) notes that even though the intersubjective model rests on a psychological experience of the body and an experiential divide between psyche and soma, the physical body and its interaction with other bodies is

where this is grounded. However, Stolorow and Atwood are at lengths to establish that mind and body are not to be seen as dualistic absolutes but instead as elements of self experience and that the boundary between the subjectively experienced mind and body is the product of specific and formative intersubjective contexts. Affective, emotional states become experienced as feelings in the mind and/or as a somatic awareness. This brings to mind the ‘confusion’ of psyche and soma apparent in ME (Driver, 2005). Overall, Stolorow and Atwood’s position suggests that ME and the effect on self can be explored not as an independent, objective truth but via the various contours of the relationality of the self that incorporates the biology of the body, other people and the materiality of the world.

The psychoanalytic ideas discussed in this section provide a psychoanalytic sensibility and way of framing the fundamental relationships between body, self, others and the material world. Psychoanalytic ideas, as part of a broader psychosocial framework, can enable the exploration of these relationships by providing not only a descriptive, conceptual language that can be developed and enlarged but also an epistemological perspective on the way that self, body, phantasy, anxiety and materiality are mutually implicated in confusing and contradictory ways. This is very important with regards to ME because it provide a means of resisting the notion that inner life can be explored and clearly understood (Lewis, 2009) whilst at the same time striving to conceptualise and understand what occurs at the boundary between the inner and outer worlds of the individual. Bringing together the ideas of Klein, Winnicott, Stolorow and Atwood enables the conceptualisation of a [psychosocial] space which transcends dualisms such as inner and outer and mind and body. It is within this space, which is simultaneously personal and social and inscribed by real material places, objects, bodies and others that self arises and is experienced in particular ways. It is by establishing ME and its effects on self in terms of this psychosocial space that is at the heart of this thesis.

In carrying forward the notion of a psychosocial space from within which to explore ME and its effect on self, the issue is how to maintain the relational integrity of the various strands of body, others, materiality, discourse and places without prioritising one over the other. I seek to explore ME experience and the aspects I have outlined in terms of ongoing relationality and process. To this end, the subsequent section outlines Actor Network Theory (ANT) as a means of tracing the associations between the

elements of experience in a way that is commensurate with my general psychosocial framework.

3.6 Actor Network Theory: a means of exploring the relationality of self

Actor Network Theory originates in the study of science and provides a model of organisation that rejects the idea that social relations are independent of the material world (Latour, 2005). ANT challenges sociologists' tendency to mobilise the 'social' as a motivating force that pre-exists the material world, which instead becomes a site on which social phenomena are enacted (Pels, Hetherington and Vandenberghe, 2002). An example pertinent to ME is the tendency for medical sociologists and ME advocates to call on 'biomedical power' or related concepts such as 'dominant discourse' to explain why ME sufferers experience delegitimation (Prout, 1996). Approaching ME from this perspective ignores the processes and material things by which biomedicine has established itself and maintains its hegemony. ANT explores such processes and how they involve dynamic relationships between disparate human and non-human, material and non-material entities or as Latour (1987; 2005) refers to them, 'actants'.

An actant is initially a non-specific entity that has a number of potential identities or 'potentialities' (Latour, 2005). When it becomes associated with other actants, distinct potentialities manifest such that the actant can carry out or aid certain actions. It is then deemed an 'actor' with a set of attributes or identities (Latour, 1992; 1997). An example might be a ten pence piece. As an unspecified actant, it is a piece of metal. In conjunction with other actants such as an economic exchange system and a human, the metal affords certain actions. It can be exchanged for things. The metal in this setting is an actor and can be described as having become networked with other actors with which its meaning and action is established; hence the term 'actor network' (Fioravanti & Velho, 2010). It is only in relation with other actors and as part of a network that a thing manifests specific identities and performs particular actions.

The concept of actor-network overcomes the dichotomy of agency and structure by implying irreducibility and this resonates with a psychosocial approach. It implies an anti-essentialist stance because any one actor, be it human or non-material, is characterised as part of a network. Unlike other sociological approaches, such as symbolic interactionism, which to one degree or another prioritise human action as determinant in society, ANT views society as networks of heterogeneous actants, some

human and some non-human, constituted through the dynamic associations and dissociations between them (Prout, 1996). The social is irreducible to either human activity or technological artefacts.

A central concern of ANT theorists is to avoid establishing a hierarchy of actors, for instance with humans seen as more important in establishing a network than material objects (Hartt, 2013). The reason for this is that if a type of actor is prioritised, it could be viewed as deterministically shaping the identities and behaviours of other actors, implying an essentialist position and suggesting that there is something unique to human agency that precedes the material world. This leads to the question of ontology.

From sociological perspectives such as anthropology and social archaeology, objects have been granted some agency but underpinning this was the belief that the motivating force always originates in humankind (Webmoor & Witmore, 2008). Objects were not privileged ontologically. However, Rochberg-Halton (1984) notes that valued material objects act as signs for and of the ongoing cultivation of the self. Objects are therefore important in their own right and across the life-span.⁹

González-Ruibal, Hernando and Politis (2011; p.2) note that the ontological relation between human and material object is important, stating that:

“...the conscious projection or communication of the self through artefacts can only be a surface symptom of a deeper, pre-existing and mostly unconscious ontological relation, in which person and thing are one.”

Considering the ontological relation between humans and material objects requires a shift from the conscious to the unconscious because:

“Ontology implies a relation between humans and things that is prior to symbolization and therefore deeper and less obvious for the human actor.”
(*ibid.* p.4).

Reflecting on the relation between the self and the material world will provide new insights into the connection between self and ME and represents a point of synthesis between an ANT and psychoanalytically informed psychosocial approach. If, from the

⁹ An in-depth discussion of the ‘sociology of objects’ and their relations to humans is beyond the scope of my thesis. How an object is distinguished from its use, how objects are perceived in consciousness, how the representation of an object is distinguished from its materiality and the degree to which surface representation as opposed to the internal complexity of an object should be considered are questions that require holding in mind for any work addressing human-material relations.

ANT viewpoint, objects are no less privileged than humans and are ontologically fundamental to human self-understanding and expression, then the implication is that the way humans interact with objects reveals relationships beyond rational contemplation. Psychosocially, this means that whilst objects may be perceived as exterior to us, they should be explored as transcending a simplistic inner/outer dualism and from an imaginative, non-rationalist perspective.

The ontological stance of ANT also offsets claims that may be levelled for instance at an intersubjective psychoanalytic stance. For example, a dualistic view is that there are *either* two separate subjectivities interacting *or* one intersubjective state. Intuitively, as discussed, people often do feel separate but equally often they do not. The issue is a false dichotomy is constructed between the individual self and an intersubjective self. From the ANT perspective this dichotomy dissolves because the various ways in which self can be experienced is an achievement that depends on the specific nature of actants, including people, which are in association at any given moment.

However, a critique commonly levelled at ANT is that it sets out a *flat ontology* which eradicates the hierarchical distinction between human and object and neglects the regulating role of social structures in shaping the relations between actors and giving them consistency and continuity (Reed, 1997). ANT assumes that there is no such thing as the social, but only actors in associations with each other (Munir & Jones, 2004). Schatzki (2002) criticises ANT by suggesting that this perspective neglects the existence of a social context that acts as a backdrop to and influences how actors associate. But, Latour (1991; 1997) argues that the issue is one of scale and that the macrostructure of society is ultimately made of the same things as the microstructures. Latour argues that ANT can accommodate different levels of analysis and can thus describe macro *or* micro structures and Akrich (1992) argues that the process of ANT exposes the mundane aspects of the social as being composed of complicated webs of relationships of actors.

Latour (1997) refers to a flat ontology as *relationist ontology*, where no entity is fundamentally more important than another. However, a criticism of relationist ontologies is that they diminish the sense of human agency and the nature of persons, denying the embodied, emotional nature of human existence (Mutch, 2002). But adopting a hierarchical ontology means having to categorise according to *à priori* structures, such as the 'social' or the 'biological', which ultimately involves a focus on

one level of the hierarchy or another. On the other hand, a relational ontology involves looking at how elements interact and how ‘wholes’ emerge from the relationships between “unique [...] individuals differing only in spatio-temporal context...” (DeLanda, 2002; p.58).

According to (Marston et al. 2005; p.422), who apply a flat ontology to rethink geographical space, the implication is that:

“...the dynamic properties of matter produce a multiplicity of complex relations and singularities that sometimes lead to the creation of new, unique events and entities, but more often to relatively redundant orders and practices.”

Collinge (2006; p.247) suggests that a flat ontology implies dynamic events of “material composition and decomposition”. In other words, a complex system such as an actor network can be seen as an ongoing dynamic event which sometimes leads to areas of order and at other times disorder, depending on whether actants are associating or dissociating from each other. Part of this will inevitably be the experiencing of emotion and the body.

Thus, a further point of synthesis between ANT and psychoanalytic approaches are that parallels can be drawn between the dynamic relations that constitute unconscious processes that remain hidden from view and similarly dynamic processes that associate material relations and space. From that position, it becomes a matter of adopting a relational ontology to bracket off the boundary between inner and outer worlds and again this is in keeping with a psychosocial framework. Approaching ME in this way provides a conceptual basis for exploring how the disparate actants that might be implicated in self experience come together, such that the experience of ME can be viewed as an ongoing dynamic event. From this perspective, self is not an innate entity that is affected by ME in an objective sense. Instead, self, ME experience, how these are conceptualised, talked about and contextualised in a material world form and transform *in situ*. Adopting this perspective is crucial to enabling a specific understanding of why each sufferer’s experience of ME is *particular* to them: each sufferer’s world of ‘things’ is different.

To frame this particularity of ME experience within an ANT perspective, I borrow the term *assemblage*. (DeLanda, 2002; Latour, 2004; Hodder, 2012). This term reflects notions of complexity, chaos, indeterminacy, multiplicity and emergence. It indicates a

growing concern, reflected in new theoretical vocabulary, with addressing the problem of determination in social processes and their inherent stability or instability (Venn, 2006). Deleuze & Guattari (1988), describe an assemblage in terms of a mix of places, bodies, voices, skills, technological artefacts, concepts, schemes and work that together make up knowledge and practice.

The term assemblage provides a metaphor that can describe the multiplicities of relations between things and is opposed to the structuring, hierarchical tendencies implicit in Western philosophy, science, psychology and history (Navaro-Yashin, 2009). Thus, the notion of the assemblage, its theorisation by Deleuze and Guattari and its subsequent development couples ANT to a psychosocial perspective. The notion of assemblage meshes with my previous discussion of psychoanalytic and psychosocial approaches to self because the relations and processes that assemblage implies transcend the mind-body dualism and the movement of actants such as viruses in and out of the material human body. From this perspective ME, ‘self’ and how ME affects ‘self’ are relational and exist as an ongoing process.

How to think about relationality in research practice connects to a broader set of theoretical debates and issues around relational ontology and requires a similarly broad outlook. For example, ANT presents a relational ontology that somewhat reflects the relational thinking implicit in psychoanalytic approaches. The manner in which actants are encouraged to describe themselves and the associations followed might be compared to the psychoanalytic notion of free association; where it serves as a projective device to explore for example the unconscious in a therapeutic setting. However, a key difference is the manner in which ANT tends towards an explicit recognition of the possibility for a multiplicitous relationality whereas classical psychoanalysis does not; which tends instead towards a more dyadic arrangement. This points towards the need to acknowledge that the idea of relationality can be ‘pushed’ further than perhaps I seek to do in this thesis, for example by developing concepts such as ‘affect’ and how it intersects with relationality (Hunter, 2012) and via authors working with feminist and poststructuralist ideas.

The notion of affect for instance explicitly addresses the relation between the social, the individual and objects from the ontological perspective. Blackman and Venn (2010) indicate a recent interest in the non-verbal, non-conscious aspects of experience

that suggests a different “type of engagement with sensation, perception, memory and listening” and ask

“...how [] can we model the psychic and sensory apparatuses that afford specific kinds of embodied knowing? If bodies are characterized by their intercorporeality and trans-subjectivity then how can we decouple such experiences from a singular, bounded and distinctly human body and what kinds of theoretical and methodological innovation will make this possible?” (p.8).

Affect is not inherent in an object but is produced as an effect of the circulation between objects and signs and objects and the body (Hunter, 2012). Affect thus outlines a pre-reflective, pre-conscious and pre-linguistic dimension that is an inherent *dynamic* of the body, requiring us to reconsider ‘embodiment’ (Blackman & Venn, 2010).

In terms of ME/CFS, affect is pertinent in thinking about the body not as a reified object but as an entangled process (Latour, 2004), implicating an affective dimension. This speaks of the way that the body can act as mediator both subjectively and intersubjectively and also of how this mediating function reflects time, space and culture. The body can be envisaged not just as a site where cultural or social processes are merely enacted, nor with reified cognitive, or rationalist elements. Instead, through affect, the body is envisioned as part of a process that ultimately avoids deconstruction because affect is beyond signification; something that cannot be read but can only be experienced (O’Sullivan, 2001).

However, Caselli (2010; p.250) states that “if affect is a way of theorizing what apparently defies narration then it is beyond critical analysis”. In other words it is difficult to stop and reflect on an affective process without reifying affect. On the other hand, affect does provide ways of thinking about and interrogating social and political processes in a different way from ones that rely on dualisms of repression/subversion (Hemmings, 2005). Hardt (1999) for example talks about ‘affective labor’ as one aspect of immaterial labour [that which produces no material goods; a service, knowledge or information about human interaction] in the context of the health services, where affective labour and care produces necessary yet somewhat intangible effects such as “a feeling of ease, well being...” (p.96). Whilst Hardt concludes that the production of affects is what gives qualitative value to the labor process it also presents the means of liberation from capitalist accumulation.

Affect is thus one example of the type of thinking that characterizes psychosocial approaches and in itself points to the way that the psychosocial field is itself heterogenous and provides a means of exploring and working with an eclectic range of material.

In this section I have described ANT from a theoretical perspective. To reiterate, the appeal of ANT is it allows me to think about humans, material objects and non-humans as coincident with each other, with a focus on the associations between these entities rather than on the entities themselves. This can lead to an understanding of the dynamic, heterogenous and particular ways in which ME is understood in terms of self experience. The psychosocial framework to this thesis represents a synthesis of ANT and psychoanalytically informed ideas which converge in the relationality of a psychosocial space where ME and self can be explored. As this psychosocial space comprises physical places and environments, it is important to explore how these have been explored in relation to health and chronic illnesses such as ME. This is the theme of the subsequent section.

3.7 The significance of spaces and places

In this section I discuss the significance of the material environment in terms of ‘space and place’ and review ideas in this area. A significant body of literature address the relations between space, place and health. Thinking about space and place is important because, as discussed previously, the perspective that I seek to develop envisages self as intimately bound up with internal, external, psychological and material places and consequently as occupying ‘space’ in a psychosocial sense.

The places where people live their lives are important and deeply implicated in self experience. Duff (2011; p.149) notes:

“Place is a fundamental feature of human experience, deeply implicated in the development of identity and belonging and central to the conduct of everyday life.”

Thrift (1999) points out the active role of place in shaping habits and situating experience whilst Proshansky, Fabian, and Kaminoff (1983) link identity to place by explaining how an aspect of self-identity is based on cognitions about the physical world which represent memories, feelings, attitudes and values. They also link place to a temporal framework by stating that at the core of such cognitions is an environmental

past which has served biological, social, psychological and cultural needs and is composed of “spaces, places and their properties” (*ibid.* p.59).

An example of a specific place that is likely to be of significance for most people is the house as home. Gulwadi (2009) explains that a stress-inducing event such as illness disrupts the familiar and meaningful in terms of everyday functional activities and also in terms of how home is experienced emotionally. Hochschild (1989) points out that the home connects to the social world, for instance in the way that it instantiates expectations of women’s gendered caregiving roles. The home is therefore a site of social, psychological and emotional significance that is comprised of different types of human, non-human, material and non-material actants.

ME has an extreme affect on people’s ability to engage physically with the world around them; most often marked during onset of the condition (Afari & Buchwald, 2003; Goudsmit, Stouten and Howes, 2009). If ME is debilitating to the degree that sufferers spend more time in their home than they did before ME onset, it is useful to think about how the home relates to their experience of ME and sense of self. It provides a physical place from which to think about the experience of ME. This meshes with an ANT-informed psychosocial perspective because place can be thought about in the same way as material actants.

It is important to consider how daily routines relate to ME sufferers’ ability to negotiate everyday environments in a functional sense; for instance whether they can climb stairs. Places can therefore be considered in terms of the activities they enable and constrain. Anfield (2011) for example describes how an ME sufferer was limited to living and sleeping downstairs because lack of mobility made climbing the stairs too difficult. Houlton (2012) notes how ME may make pushing a vacuum cleaner difficult. ME presents as functionally impairing in terms of daily routines and engaging physically in the home. However, one’s relationship to the home-as-enabling-place reflects not only demographic variables such as class, ethnicity and family size but also an increasing politicisation of that relationship and its restorative function (Csikszentmihalyi & Rochberg-Halton, 1981; Williams, 2002; Thrift, 2004). This suggests that people’s relationship to the home is a site of social organisation, which fits with an ANT perspective and how it can be used for instance to think about the social relations between the material environments, people and their sense of self in light of discourses around ME.

Whilst the home is important in terms of daily life and well-being, there are also many environments beyond the home that ME sufferers may engage in. These also need to be considered in terms of daily routines. For instance, a wealth of literature focuses on *enabling places* in terms of health-promotion (Smyth, 2005; Duff, 2011). Enabling can be understood in terms of restorative therapeutic functions and restoring diminished functional capabilities and resources (Hartig and Staats, 2003). Enabling places and environments have the ability to mitigate stress, anxiety and aid mood regulation (Hartig & Saats, 2003; Milligan & Bingley, 2007; Williams, 2007). Laumann, Gärling & Stormark, (2001) for example found that natural environments enhanced well-being more than urban environments. Korpela et al. (2008) suggest that the restorative capacity of favourite places reflects complex associations between renewal of directed attention capacity, physiological changes from tension and stress toward relaxation and positive mood change. Such places are also connected to personal background of nature experiences, such as nature orientedness and childhood experiences and duration and frequency of being in the favourite place. This implies the need to focus on the particularity of relationships with given places.

Interestingly, Casey (1996) suggests that space can be reframed as an ‘event’. This is the idea that at the centre of place is an experiencing body that dynamically engages through the senses with the environment and the things in it. This relationship between the two is never static. Similarly, Pink (2008; p.246) claims that:

“...paths and routes are not simply functional routes that connect one place to another, but are meaningful sensory and imaginative places...”

This urges a rethink of places not as distinct, static areas but as a process which implies the moving, sensing body, others and objects. It is interesting to note how Pink intimates the metaphorical status of paths and routes as well as their literal status. The implication is that the path/route somehow connects things and at the same time is transformative beyond immediate sensory experience. This resonates with the relational premise of ANT in that the identities and actions that result as actants come into association reflect how actants associate, rather than the actants themselves. Moreover, re-imaging material places in terms of transformative psychosocial spaces necessitates an appreciation of the way that metaphor can be used as a means of generating fresh insights and understandings (Aita, McIlvain, Susman and Crabtree, 2003). The relevance of a psychoanalytically informed psychosocial framework is that

it already holds open the door to thinking about the relationships between self, place, objects and others in imaginative, metaphorical ways.

In summary, there are important connections between spaces, places, health and the experience of self. These connections appear to be complex and incorporate social, temporal, emotional, cognitive and physiological factors. Given the premise of ANT and the close relations between people and their home, an understanding of ME can focus on the actantial arrangements between sufferers, their everyday environments including the home and the things in it as a site where emotions and experiences are mobilised. This brings my methodology into the lived world of the ME sufferer and provides an experience-near perspective (Schneider, 1999; Hollway, 2009; Lewis, 2009). The home can be envisaged as a dynamic, psychosocial space where ME and self are coincident and reflect way that specific actants move into and out of association with each other.

3.8 Summary of research rationale

In this section I summarise my theoretical perspective by outlining and drawing together the various conceptual strands discussed in this chapter.

In terms of self, I draw on postmodern and poststructuralist notions to envisage the relational, situated, shifting and non-unitary nature of self as coincident with the activities and contexts that people are engaged in. This view challenges a rational and essentialist model of self but adopts a critical perspective of the disparate aspects of micro and macro discourse such as social policy and power as well as more psychological aspects of emotion and cognition. It enables an understanding of the meaning of situations and processes through which ME and self are experienced by the sufferer. To make sense of the social and relational aspects of self necessitates exploring the part played by non-human objects and the material environment as these form part of the semiotic system through which self is constituted.

ME transcends characterisation as psychological, social or physiological and involves contested relations between mind and body. Many aspects of ME are confusing and contradictory and there is an entangled relationship between the beliefs of clinicians, researchers and sufferers and the nature of aetiological models and treatment options. From this perspective, ME will be approached as a complex, dynamic arrangement in which the researcher becomes implicated. A methodology that is inherently reflexive is

necessary. Because of the potentially irrational aspects of how ME is experienced and to avoid implying that ME can be explained by social processes I will draw on psychoanalytic ideas as a means of thinking about and exploring the felt, unconscious and confusing aspects of ME and self experience that are not representable through discourse. In this way, an understanding can be developed that retains some interiority of self.

Psychoanalytic theory is drawn on as it provides a means of thinking about and re-articulating the mind-body schism. Body and mind need to be thought about in the same ontological register so that a non-dualistic understanding of the effect of ME on self can be developed. The works of Klein, Winnicott and Stolorow and Atwood have been drawn on as a means of conceptualising a space that sits across the boundary of the inner and outer world. This enables me to think about the relationality of body, mind, others and external material objects as a dynamic arrangement and brackets-off questions of aetiological causality. Thinking about a psychosocial space which transcends mind and body and through which self is effected enables a consideration of the broader cultural and discursive field and provides a means of articulating metaphorically how seemingly disparate and ontologically incompatible things such as viruses and lay-beliefs come together.

Psychosocial thinking provides the framework through which ME and its effects on self will be explored. A psychosocial stance envisages self as a meeting-place where social, psychological and physiological aspects of ME are experienced. This enables an equal-handed treatment of the social and psychological aspects of ME. Psychosocial thinking is drawn on as it promotes creative ideas about the relationships between psychological and sociological processes, and their mutual infusion, in a non-reductive manner. This relates to an ANT purview where all entities that ME might be compromised of can be given equal consideration, overcoming the dichotomy of agency and structure that ME implies.

ANT provides an anti-essentialist stance where any one type of actor is no less important than another. Adopting a relational ontology and reflecting on the relation between self and the material world will provide new insights into the connection between self and ME. As ANT promotes a descriptive language in keeping with the voices of the actors it represents, I seek to develop descriptions of ME that reflect the experiences of ME sufferers in a way that is particular to each sufferer. This is a way

of staying with the similarities and differences in the ways that ME is experienced and articulated.

Finally, I draw on research that considers the importance of spaces and places. The places and environments in which people live and frequent are important and implicated in how self is experienced and the identities that are involved. The home is a place of social, psychological and emotional significance that contains many human, non-human, material and non-material actants and provides a physical place in which to think about the experience of ME as part of the relationality of the ANT frame.

Chapter 4

Actor Network Theory and metaphor: the methodological premise

4.1 Chapter overview

In chapter three I discussed ideas about self and self's relation to ME, which lead to an outline of ANT along theoretical lines and why it lends itself to a psychosocial framework. My aim was to describe ANT's main constructs and its premise of seeking to understand the relationships between materiality and social life. Anti-essentialism informs ANT's conceptual frame for interpretation as well as guiding the methods used to trace networks (Ritzer, 2004). However, ANT is often cited as being a method as well as a theory (Latour, 1999; 2005; Dicken et al. 2001; Ritzer, 2004). To a certain extent this is due to ANT having no unified body of literature and being somewhat eclectic in its application and interpretation (Pollack, Costello and Sankaran, 2013). ANT does not seek to explain why an actor-network takes the form it does. Instead, it offers a method of exploring and describing the relations between actors rather than an explanation. Thus, whilst ANT rests on certain theoretical constructs and provides a general heuristic which leads to its theoretical status, its value for me is as a method to explore ME. However, ANT might be critiqued because of its apparent apolitical stance and because of the manner in which it suspends recourse to a priori social categories' such as gender and class. According to Gad (2010) ANT has been challenged by feminists for focusing on privileged actors and for overlooking other ways in which networks may develop. Thus, a significant portion of the first part of this chapter addresses such critiques and how alternative perspectives on categories, such as psychosocial feminist approaches, require acknowledgment because of the way that they bring to attention and frame such issues.

In this chapter I outline my methodological premise, describing how to notice and think about the relations between actors in the ANT spirit. Developing a methodology that could accommodate the potentially confusing nature of ME (Robinson, 2003; Dickson, Knussen and Flowers, 2008) involved synthesising ANT with psychoanalytically inspired ideas. With this in mind, the second section of this chapter discusses the nature of metaphoric and metonymic processes and how they relate to Freudian ideas. I then discuss how contemporary work links metaphor to primary

somatic experience before outlining how I use metaphor to trace associations between actants. My assertion is that the grounds for action and experience, for example those which an ME sufferer are involved in, cannot be reduced to a conscious choice occurring in an isolated mind but can instead be thought about in terms of the associations between actants (Latour, 2005; Pollack, Costello and Sankaran, 2013). I conclude the chapter by drawing attention to the subtle and complex aspects of metaphor and metonymy and how oversimplification must be avoided when using them to explore the narratives of ME sufferers.

4.2 Actor Network Theory as method

Given that actants become relationally involved with each other in an actor-network, central questions are how to discern if something is an actant and how to find out what it associates with. In this section I address these issues and explain how they form the basis for my methods.

Latour's empirical slant is always to follow what objects are doing in their particular context of associations and to describe what is noticed (Harman, 2009); reprised in Latour's directive to *follow the actor* (Law 1992; Latour, 2005; Fioravanti & Velho, 2010). Following the actor is the process of focussing on an actant as it associates into a network, noticing the actions it is involved in, how its identity emerges in association with other actants and by paying attention to the language with which actants describe themselves.

With this in mind, Latour (2005; p.147) states that:

‘... actors themselves make everything, including their own frames their own theories, their own contexts, their own metaphysics and even their own ontologies.’

Because actors build their own worlds, researchers cannot identify actor-networks unless they enter them, which involves approaching actors as far as possible on their own terms (Law, 2003). This promotes a reflexive stance to the research because the researcher has to consider the part they play in interpreting what they notice. Concerning ME, prioritising what is of importance to the sufferer and not questioning the veracity of their accounts by looking for inner psychological explanations is vital. By allowing the sufferer to delineate what is important to them the researcher may

encounter a previously unconsidered range of material and non-material aspects implicated in that sufferer's particular experience of ME.

ANT is flexible because it considers all actants, material and non-material, as equally important in understanding social relations and specific experiences, such as ME. Latour (2005) refers to this as *symmetrisation*. Symmetrisation implies that ANT theorists should apply a single explanatory framework when describing and interpreting what actants are doing and that no human actant is any more important to the network than a non-human actant (Ritzer, 2004). Symmetrisation provides a useful heuristic in approaching ME because it enables consideration of all and any entity as potentially important be they viruses, sofas or symptoms.

The principle of symmetry connotes that neither humans nor non-humans are able to act with agency alone. I characterize agency as the:

“...collective capacity of heterogeneous networks, in which the activities of the non-human may count for as much, or more, as the activities of humans” (Ruming, 2009; P.456).

In other words, there are always many entities implicated in a specific action and no single entity, human or otherwise, is capable of action or effecting a specific outcome on its own. This perspective on agency avoids establishing a specific actant, such as a virus or a pre-existent personality type, in an aetiological role in ME.

The principle of symmetry is extremely important in ANT studies for the reasons outlined previously, but it also needs to be thought about in terms of its broader ramifications and work that comes ‘after’ ANT (Law, 2004). For example, symmetrisation enables the making of material and non-material actants equivalent to the effect that all and any entity has to be approached in terms of its associations and resultant effects at the network level and not in terms of preconceived notions about its nature, capacities or likely effects. However, there are implications for assuming such equivalence and attempting to avoid engaging with existing categories that might be seen as determining the identity of an actant. Haraway (1988) is useful in drawing attention to how, if equivalences are drawn for example between the categories of gender and science, common language or heteroglossia or by extension material object and non-material object, each term obscures a structuring, binary opposition that rests on difference and the illusion of mutual exclusivity; the terms exist in a dialectical

relationship. To take an example which might apply to this thesis, my recourse is to bracket off categories such as gender to avoid being seduced by existing ‘genderised’ ME discourse. Existing discourse might include that of sufferers being predominantly female with the implication that female sufferers are simply tired from working too hard, as has actually been implied by epithets such as ‘tired woman syndrome’ (Maran, Lawson and Hill, 1962). The question is whether bracketing off categories such as gender and by adopting symmetrisation as an heuristic results in other problems?

One observation on symmetry is that it “is not to substitute the great divisions for a transcendent unity, but to recognize the little differences that the great divisions over codify...” (De Castro & Goldman, 2012; p.430). This brings the focus back to the particular and local in a way where the effects of broader categories such as gender are instantiated. However, it is undeniably the case that gender does play a role in how ME is experienced. What is at stake is how best to understand this tension. Law (2004) is useful here. He uses the term *method assemblage* to connote the messy, fluid and entangled relations of reality and the devices and understandings that it produces. Applying this approach to ME, it is not the case that ME exists as an homogenous object. It is instead crafted and assembled as part of a hinterland; as part of the broad background of investigations, practices, statements, beliefs and methods through which ME is established and understood. Through this enactment or crafting [which creates ME as a presence] is also the creation of manifest absence and Otherness (Law, 2004). The presence of ME is fatigue, post exertional malaise and so forth. Its absence, which its presence depends on, includes its genderised history. In this sense, gender, even if it is not salient as a research focus, remains present as an absence and this segues into what Law describes as absence that is not manifest; Otherness. This Otherness disappears because it perhaps becomes ‘routine’ (*ibid.* p.85) or because what is brought into presence can only be maintained because it is Othered and, as Law notes, this suggests Otherness taking the form of a repression. In this sense, gender remains as a necessary category because it delimits that which it is not; albeit one in this thesis that I have purposely bracketed off for reasons explained previously.

A further benefit of ANT concerning ME is that it can:

“...sensitise researchers to complex and multiple realities which might have otherwise remained obscure” (Nimmo, 2011, p. 109).

This sentiment urges ME researchers to avoid foreclosure of ideas and to be open to the possibility of multiple interpretations of each case. The equivalence I draw between this statement and how I think about self is that I view self as an outcome or effect of many actants networking in specific ways. From this position, self has multiple contours that reflect its inherent relationality. How self is experienced reflects specific actor-networks that the human actor is part of. Thus, depending on how stable these networks are and what they comprise, self will be experienced at times as constant whilst at other times as more fluid.

However, there remain some questions concerning the apolitical and anti-essentialist accounts that ANT might be seen as producing. These questions are pertinent given the historically gendered nature of the ME debate. They concern different approaches that, whilst acknowledging the ways that ANT has managed to push such agendas forwards, posit alternative points of consideration. For instance, despite the attempt to avoid establishing the salience *á priori* of objects or categories, such as gender, class or ethnicity, bracketing off such categories means that where these categories have effects for people forecloses an important avenue of analysis. According to Singleton (1996) the non dualistic and descriptive vocabulary of ANT and the symmetrisation of human and non-human does not promote change nor the uncovering of the oppression and inequality experienced by various groups. Also, ANT eschews the use of categories and dualisms, the caveat of which is that power is represented as a consequence of action, not a cause.

So approaches which come ‘after’ ANT (Law, 1999; 2004) share a commitment to uncovering and redressing the oppression and inequalities that can characterise the experiences of certain groups. Later, or post-ANT approaches also seek to denaturalize existing relations and interfere “in dominatory practices by articulating alternative politically hopeful or liberatory tropes” (Law and Singleton, 2014; p.380).. As noted by Star (1991), networks may be heterogenous and involve heterogenous actors, but heterogeneity is different for the privileged compared to the non-privileged. More recent studies which challenge and develop ANT also acknowledge the affective, complex and messy nature of what might otherwise be seen as relatively harmonious networks. This is important because, as implied by Hunter (2012), without paying attention to such complexity and the affective dimension, analyses themselves can

produce sanitised versions of experience that fail to reveal the effects of power on certain groups.

Drawing on feminist material semiotic and critical race theory, Hunter's (2005) feminist psychosocial approach makes a space for a human dynamic founded on emotion and the relationality of a space in between the social and the individual. By focussing on [self] governance, Hunter indicates how categorisation relies on the entanglement of things like biographies, cultural orderings and personal histories. This involves the irrational, affective and emotional and provides for a personal relation to governance; one that is a product of very particular socio cultural and affective contexts and histories and is entangled with conflicted, emotional processes. From this perspective, categories that might be pertinent to ME, such as 'female' are not homogenous in the sense that they delimit specific aspects of ME experience. Instead, they point to the multiplicity of experience and identity and the manner in which categories constitute and are constituted by affective, relational processes in the first place.

Hunter (2005) also distinguishes between what she sees as the multiple ontologies that arise through recognition of an enacted and particular set of experiences and the categorical dimensions through which an individual recognises themselves. In other words, subjectivity spans both ontology and category. This notion of relationality, premised on unconscious processes and a psychoanalytic influence that is commensurate with this thesis brings the biographical, social and situational into the same analytical frame. It shifts the analytic focus away from the recognition of sameness and difference considered in categorical and ontological formations to connection and differentiation as the principles of social relationships. The implication for multiple ontologies is that they arise with multiple realities. But that is not to contrast what I have discussed previously in terms of the relational ontology of ANT. My recourse to a relational ontology aims to provide an heuristic starting point from which to 'follow the actor'. That is not to claim that for each different sufferer there is the same experience of ME. In this sense, the reality of ME is multiple; with each actor involved in their own specific ontology.

So the idea of multiplicity draws on a different set of metaphors inclined to intervention and performance and suggests a reality that is enacted and done, rather than observed (Mol, 1999). There is thus a politics of the ontology of ME in that the

organisation of the detection of ME is not just a practical matter. The way that this occurs affects the reality that the ME sufferer experiences and even how ME is talked about. For different sufferers of ME, the subjective experience of the condition rests with entities and tests which provide the 'facts' of their ME and yet these facts are founded upon an already politicised deployment of the material actants, such as tests and questionnaires, that these facts have enrolled. Singleton (1996) suggests that to enable the different voices and the conflicting and contrasted identities that are implied by the previous discussion and enable a view of the multiplicitous nature of the network, the focus needs to be shifted towards multiple actors.

Psychosocial feminist approaches highlight the dangers associated with adopting an apolitical stance. The problem is that by assuming the political neutrality of categories and objects shifts their potentially deterministic character to one where they are impotent or appear to have no effect at all. This undermines the effect that they *might* actually have on how experience is organised for certain groups of people. Gill (1996) claims that an apolitical stance misses a 'middle ground' that could be productive and goes on to note that if from a post-essentialist perspective there are no epistemological grounds for arbitrating between truth claims, then how are any claims to be evaluated?

What the preceding discussion flags up is that despite my deployment of ANT and how I attempt to bracket off existing categories such as class or gender, there are different ways of doing this which adopt a much more critical approach. The key issue is that what is presented as structure/agency in ANT is framed through other debates as one of power/resistance and which can provide for a different analytical approach. But it is also worth echoing Gad's (2010) observation that ANT does not represent an heterogeneous body of work. Its nature means that it should always be in state a transformation and reflexive self-questioning. This means that whilst there may indeed exist inequalities, oppression and an inherent political dimension in many of the arenas which it had been applied, this may not always be the case. Gad claims that the question of ANT's apoliticality cannot be solved by enforcing a viewpoint upon it and that opens up an ethical debate which I believe is beyond the remit of this thesis. However, according to Law and Singleton (2014), ANT demonstrates an analytical *and* political sensibility that enables it to reconsider taken for granted assumptions about, the social, the political and the natural. In this sense any ANT project is necessarily engaged in political work.

In terms of methods, the first issue is to identify a point of entry into the network. ANT studies often concern the success or failure of specific technological innovations or organisational structure or a problematic state (Bleakley, 2012). The starting point of an ANT study is often the problematisation of a state of affairs, with the research aimed at describing the problematic state and what transpired. Retaining this broad premise, my entry point is that ME represents a problematic state that can be described as a particular arrangement of actants and resultant experience. ME is already problematised because it remains a highly contested condition. The best point of entry is to follow the principle actant from its perspective. This is the sufferer and where they spend most time: their home and other significant places in their daily lives.

Once the researcher has met the ME sufferer the task is to notice, observe, listen to and make sense of what suffering ME entails. The concepts, objects, experiences and places that become known can then be thought of in terms of actants. For instance, asking the sufferers I worked with to narrate their experiences with ME resulted in talk about symptoms, viruses, activities, specific places, family members and a range of material objects. Each of these can be thought of as an actant that required following because the task was to find out how they associated with each other and coalesced into an actor-network.

However, an important aspect of following the actor is that some actants appear as if they have transported or displaced themselves in form, time or space (Callon, 1986; Latour, 1992). *Displacement* is a central idea in ANT studies. To illustrate this concept, Latour explains how an automatic door closer replaces a human actor by performing the same function. The door closer has had displaced into it the human capacity to close a door and under the right conditions, as part of a door and with other actants such as a wall, it can close a door accordingly.

Displacement speaks of how a function, behaviour or competency has been reconstituted into another place or thing. A further example given by Callon (1986) is how scientists displace their ideas and theories into charts and graphs, which they use to convince others that their ideas are worth adopting. But this reconstitution also implies that a transformation has occurred. In the previous example, the door closer acts as a spokesperson on behalf of the organisation of actants, including humans, which led to its physical form and mode of action. It represents the aims of these other actants and acts on their behalf but it does this through its own material capacities.

Thus, the door closer has translated the language and behaviour of what human actants say or want (Latour, 1988; Pollack, Costello and Sankaran, 2013). Given the psychoanalytically inspired aspect of my psychosocial framework, I find parallels in the ANT notion of displacement with Freud's psychoanalytic concept of the same name.¹⁰ Displacement therefore represents a point of synthesis between ANT and psychoanalytic ideas.

How does ANT address the notion of displacement between actants? Displacement represents a physical, social or psychological transformation and movement from one site to another, occurring as a dynamic process of various actants coming together and jostling into position as a network. This process as a whole is referred to as *translation*, where the identity of actors and the possibility of interaction and salient identities are fought over, negotiated and delimited (Callon, 1986; Ruming, 2009). Translation invariably involves actants altering a state of affairs. According to Latour (1999, 2002), any actant that *mediates* between actors will modify the relations between them. If the focus is on associations and resultant action it follows that the intervening actant is also altered in terms of what identities it can manifest, dependent on what it is associated with. This perspective facilitates the exploration of a condition such as ME because it shifts the focus from a structural attribution of the roles played by discrete entities to one where the identity of given entities are mutually constitutive and dynamic.

Translation consists of four moments; *problematization*, *interessement*, *enrolment* and *mobilization*. These moments describe elements of a process that are inseparable from each other and detail how actants come together as an actor-network. As an overarching metaphor they frame the methods I develop for noticing things in the experience of the ME sufferers in this research.

¹⁰ See for example Freud (1900); Robbins (2004). Displacement in a Freudian sense describes an unconscious process and defence mechanism whereby an intolerable affect is redirected towards an object or person, instead of the object that the affect is actually associated with, because it is less threatening to the ego to do so. Importantly, the process of unconscious displacement transforms the affect and its object and presents them to consciousness in an altered form that *may not* appear meaningful. The process of displacement is essentially metonymic. The significance is that chains of displaced signifiers can be linked together such that what is manifested is apparently removed by several degrees from what was originally displaced.

Firstly, problematisation is the defining of a problem in terms of a specific actant (Tatnall and Burgess, 2002; Sarker and Sidorova, 2006). The specific actant becomes defined as a means by which the problem can be solved and as such becomes indispensable to the network and the solution. It also defines other key actants with the problematic in question (Linde et al. 2003) and attempts to make itself indispensable; becoming an *obligatory passage point* (Callon, 1986; González, 2013) and imposing its view on others. Beyond establishing ME as a problematic state, I also use the term problematisation to think about an event, actant, or question that arises from the data and that appears to be pivotal in the state of affairs regards ongoing experience and ME.

The second moment, *interessement*, describes the way that an actant attempts to impose and stabilise the identity of other actants or aspects of the network by attempting to get other actants to accept its proposal (Callon, 1986; González, 2013), or in other words it “attempts to impose and stabilise the identity of the other actors it defines” (Callon, 1986; p.8). Through this process, actants that support the network begin to fix other actants into place (Tatnall and Burgess, 2002). They also weaken the influence of actants that conflict with the interest of the central actor (Linde et al. 2003). The resultant network is precarious because actants can always act in unpredictable ways. A network is therefore dynamic and actant identities are simultaneously transient and intransient, which avoids establishing an actant or a network as stable and reified. When applied to ME, this perspective enables the researcher to reflexively refine and negotiate their ideas about what they notice and what the sufferer tells them as new actants are added to the network and existing ones altered.

Enrolment describes the degree of success of the *interessement* in that various actants have been co-opted into the network in certain relationships and accept the identity that emerges from their relation to each other (Callon, 1986). Characteristic of ANT studies, it is here that there exists talk of power relations, of the means of maintaining the *interessement* and the identities of the actants involved. Callon (1986; p.211) describes this as:

“...negotiations, trials of strength and tricks that accompany the *interessement* and enable them to succeed”.

Enrolment involves the ongoing moves to ensure that aspects of desired identities are highlighted whilst undesirable aspects are diminished (Law, 1986b). Enrolment represents the network settling into a stable state as long as negotiations between the actants are successful and their identities are accepted (González, 2013).

Finally, *mobilisation* speaks of the way that the previous moments of translation are substantiated into the overall effect or solution because the controlling actor has accumulated enough allies to modify the behaviours or beliefs of all others (Latour, 1990). The identities of actants might undergo a series of displacements of form, place and space via a series of other actants. As Donovan (2000) notes, when a researcher presents a paper at a conference, the paper stands in for all the research and other researchers and actants that it rests on. For all these other entities to remain mobilised, forming a stable network, the researcher has to carry out ongoing translations to ensure their continuing enrolment and silence that which is not desired.

In summary, ANT provides a method of noticing and explore the ways in which different actants in the world of the ME sufferer come together and how these become displaced across time and place. Translation provides a metaphor to frame the research process and how actants might co-opt or suppress other actants such that the heterogenous field of things that make up the experience of ME come together as specific actor-networks. Translation frames the overall description of my findings. In this sense, translation speaks of the research process and the report arising from it (Ruming, 2009). As I move through the research with a particular ME sufferer I use the concept of translation to notice specific actantial associations to the point where interpretations can be made. Translation frames how actants associate and stabilise into an actor-network and how the end of the research process involves describing the actor-networks that emerged and hence the sufferer's particular experience of ME.

In the subsequent section I discuss displacement in light of ideas about metaphor and metonymy. The psychoanalytic concept of displacement can be synthesised with ANT and developed as a means of thinking about the apparently contradictory or opaque ways that one actant may associate with another.

4.3 Metaphor as a means of following the displacements between actants

As an example of Freud's notion of displacement, a child may feel unconscious aggression towards its father but acknowledging this hostility induces too much

anxiety. The hostility is redirected towards the family cat, which the child kicks. What the child takes away is that the cat was kicked; perhaps not fully aware of why they kicked it. In terms of observable behaviour it is likely that an onlooker has no awareness that the original affective relationship that motivated the kick was between child and father.

Displacement in the psychoanalytic sense provides a way of thinking about how things might associate in unconscious ways that are beyond conscious understanding and hence beyond rational explanation. ME lends itself to exploration in this manner because of its variable and confusing character, given that it is not clear how someone can suffer no apparent physiological insult and yet proceed to manifest a range of somatic and psychological symptoms. The commonality that allows synthesis of ANT and psychoanalytic perspectives is that they connote processes whereby something is translated into a different form. This brings to mind the notions of *metaphor* and *metonymy*.

Metaphor is a figure of speech which describes a subject by conferring on it the properties of an unrelated object that are not literally applicable. For instance, ‘the wheels of justice turn slowly’. Justice does not literally have wheels. In literary terms the use of metaphor is creative, opening up new ways of description that create new understandings and visualisations. The character of the metaphor itself is important in that the greater the difference between the subject and the object of its comparison, the more powerful it is because work has to be carried out to make sense of it in linking objects or concepts that do not immediately appear compatible (Stern, 2001). One way of thinking about the differential aspects of such concepts is that they inhere in different *domains* (Lakoff & Johnson, 1980; Glucksberg & McGlone, 1999; Stern, 2001). For instance, in the previous example, ‘justice’ is an abstract concept in one domain but ‘turning wheel’s’ exists as a mechanical device in the domain of material objects. Metaphor establishes relations between concepts or objects in different domains. Significantly, this implies that human relations to material objects are often metaphorical.

During Freud’s development of psychoanalysis, metaphor was a linguistic device; a literary trope. But in the psychoanalysis of the 1930s and 1940s, metaphor use was part of the symbolic process of clinical description and treatment of the unconscious (Aragno, 2009). The act of psychoanalytic interpretation also involved translating

between different domains. A relevant example of the psychoanalytic interpretative process involving a metaphoric translation between two domains, soma and psyche, is given by Driver (2005). Driver describes the analysis of a young woman with ME who manifested severe headaches. Eventually, Driver began to experience bad headaches during analytical sessions. Driver interpreted her own headaches as the analysand [patient] wanting Driver to know what they felt like so that she could ‘unravel’ them. However, this interpretation when offered to the analysand caused anxiety. Driver felt this revealed a lack of a ‘maternal object’ or internalised mother-figure, on the part of the analysand.

What this example illustrates is not only a metaphoric translation from a headache [somatic] to a psychic experience [understood as ‘unravelling’], but also that the unconscious metaphoric process acts as a means of communication and relating. If relations between people and objects are inherently metaphorical and objects and experiences are themselves understood metaphorically, then it is reasonable to explore ME in terms of the relations between the body, material objects and material places.

It is the transfer between different domains that constitutes the metaphoric and in doing so establishes relations of similarity and, by negation, relations of difference. The polysemous qualities of any object that the subject of metaphor references and the potential for more than one meaning or understanding to arise from it provides a sense of the fluid, dynamic qualities of metaphor and their idiosyncratic deployment and uptake. Freud (1900) was fully aware that the ambiguity of words allowed them to act as a point on which numerous thoughts might converge. Hence, the scope for multiple relations and interpretations of these relations.

Ricoeur (2003) suggests metaphor invites a new organisation and understanding of the subject and object of a metaphor, but with the ever-present carry-over or residue of the original organisation. In other words, something of the original metaphor persists. This implicates memory and the temporal dimension of metaphor. In other words, via metaphor, an affect or object that existed in the past can be said to metaphorically displace itself to exist in the present. This is important because it provides a way of thinking about the relations between objects and concepts that a sufferer of ME holds as important today but which may have their origin in a previous time. However, that is not to say these relations are necessarily causal. My concern is to think about how actants displace themselves and exert an effect as an overall part of an actor-network,

not as an isolated and agential entity. Applying a metaphoric frame provides a way of thinking about how things as actants come together and what might be effected for that particular ME sufferer.

A literature review of metaphor in terms of its functionality, what it allows people to do and how it is deployed, revealed an extensive body of writing. The conclusion I came to from this review was that the field of metaphor studies is vast and to focus on the finer detail of metaphor function was beyond the remit of this thesis. However, the review enabled me to think about how I might use metaphor to trace the displacement between actants and also how ME sufferers may deploy specific metaphors and even how metaphor reflecting specific cultural viewpoints may be reflected in specific language.

Studies concerning the link between metaphorisation and language include Schachtner (1999; 2002) who investigated diagnostic and therapeutic strategies among general practitioners concerning how linguistic images guided interaction with patients. Beneke, (1982) investigated how convicted sexual abusers' use of metaphor reflected a specific understanding of and stance towards sexual violence, such as terms which refer to women as things to control or to hunt, for instance "what a piece of meat". Thus, metaphor use goes beyond mapping between domains such as the material to the psychological. It informs many aspects of culture, how people understand themselves, inter-relations and even research strategies (Schmitt, 2005). From the perspective of a case study, metaphor analysis is commensurate with biographical research (Kronberger, 1999) and hence the particular perspective on ME experience which I seek to develop.

Metaphor, in contrast to *metonymy*¹¹, refers to relationships consisting of a source being equated figuratively with a target located in a different domain such that the literal equation is meaningless, whereas the figurative equation is meaningful. Metonymy on the other hand refers to a source being equated with a target located in

¹¹ According to Catalano and Waugh (2013), the study of metonymy has been overshadowed by metaphor and some theorists view it as a sub-category of metaphor and not a category on itself (Searl, 1993). Benczes et al. (2011) asserts that metaphor and metonymy are difficult to distinguish from each other and that they often interact in linguistic settings. This makes some instances difficult to analyse. The reason I consider metonymy and metaphor in different lights is that they enable me to think about displacement from an ANT perspective in different ways and also because of their pivotal role in psychoanalytic theory.

the same domain. Hence, in a metonymic sense, ‘The White House’ stands for or literally represents the U.S government and policy.

For Freud, metaphor and metonymy were the basis of the unconscious, although Freud referred to them as *condensation* and *displacement* (Freud, 1900). For Freud, in terms of a dream, *condensation* was the process of metaphorisation, with the properties of objects or persons in one domain, conveyed as a single subject in a different domain that was not literally equivalent. Hence the manner in which the dreamer describes one single figure in their dream as comprising several characteristics or features of several others known to them. Displacement on the other hand was akin to metonymy, where one object literally stands in for another and is felt as such. It is identical. In a practical sense, Freud (1905; p.5) refers to *switch* words to refer to a word or phrase which appears perhaps often in a given person’s talk and serves as a nodal point on which various unconscious and conscious thoughts converge. A switch-word thus ‘reveals and conceals’ the true meaning of a dream or symptom (Litowitz, 2013; p.2). Paying attention to how an individual uses words [repetitively] and thinking in terms of switch-words provides a method of tuning into how things may be metaphorically and metonymically related.

So psychoanalysis proceeds on the basis that the analysand signals much about their unconscious states via what they say, what they do not say and their bodily, non-verbal communication (Wachtel, 1967). For example, an analysand may report ‘feeling down’ and shift their body to reflect this. There is thus a metaphoric/metonymic relation between talk and body that can be discerned by paying attention to both. From a Kleinian perspective, talk often reveals a *defended subject* in that the speaker employs unconscious defences to guard against anxiety that otherwise undermines certain aspects of identity or self (Hollway & Jefferson, 2000; Lillrank, 2002; Frosh, Phoenix and Pattman, 2003). Whilst I do not adopt the notion of the defended subject *per se*, I note its ubiquity in psychoanalytically informed psychosocial approaches and its use in drawing attention to how anxiety may delimit talk.

Contemporary work in psychoanalysis has moved metaphor and metonymy centre stage to establish a common basis for various psychoanalytic schools by rethinking psychopathology in metaphoric and metonymic terms (Borbeley, 2004; 2009; Modell, 2003; 2009; Montana Katz, 2011). For example, Borbely describes normal mental functioning, with access between the same situationally or praxis-defined domains, as

positive metonymy. He describes *negative metonymy* as central to psychopathology, such that mental content in one temporal domain [present] is denied access to content in another temporal domain [past].

For instance, if an individual suffered an abusive relationship with their father [an authority figure] as a child, this may come to metonymically stand for their relationships with authority figures in the present. The individual experiences present relationships in the same way as they experienced the father. The premise of psychoanalysis is for the psychoanalyst to tune into unconscious processes with the analysand and to bring to light unconscious material that enables the analysand an insight resulting in a new, healthier affective and cognitive self-understanding (Frosh, 2002). Listening to what ME sufferers say, in this light, is one way of tuning-in to how disparate actants and past and present are associated with each other.

As the body is thoroughly implicated in ME it is important to think about the connections between it and metaphor and how these have been explored. To this end, one area of contemporary work on metaphor has looked to primary somatic experience as the ground for the development of thinking and later experience, which are both inherently metaphorical (Lakoff and Johnson, 1980).

Over recent decades much work has been carried out to conceptualize the relationship between linguistic metaphors and how they might develop from or in parallel with physiological development and experience in the material world. This developmental movement involves primary somatic experience that becomes metaphorised and symbolized through linguistic means. Research which originates in the cognitive and linguistic disciplines suggests that language is inherently metaphorical and that its development originates in the basic somatic experience of the neonate (Feldman & Narayanan, 2004; Lakoff & Johnson, 1980, 1999; Grady, 2005). Freud (1911) had already proposed that thinking was a psychic elaboration of motor action and so it is necessary to briefly outline Freud's ideas on symbolism and how it connects psyche and soma.¹²

Freud's early work established symbolism as a largely unconscious transmission process involving the defensive substitution of one thing for another, namely displacement (Petocz, 1999). For Freud, the basic language of the mind was the

¹² See for example Freud (1923; 1937).

unconscious and this was rooted in sensory and somatic processes (Robbins, 2004). The capacity to think and for consciousness and language use was the result of a developmental process whereby the underlying unconscious processes rooted in bodily experience make themselves known to consciousness in a symbolic form. These symbolic processes manifest for example through dreams, hallucinations and wishes. In this vein, Grünbaum (1986) points out that symptoms, such as those an ME sufferer might experience, have traditionally been viewed as non-semantic symbols in that they represent a substitute outlet for repressed unconscious material. That is not the perspective of this thesis but the importance of Freudian ideas is that they connect the body via symbolic processes to thinking and the experiencing of something from one domain in another. Such ideas are foundational to later work on the connections between body, thinking and metaphor from other perspectives, such as Lakoff et al. (1980, 1997).

From the cognitive perspective an explanatory hypothesis is that subjective (non-sensorimotor and non-proprioceptive) experience and sensorimotor and proprioceptive experience are initially undifferentiated. Sensorimotor refers to motor activity caused by sensory stimuli and proprioception refers to awareness of one's body position. In a baby, the way in which it experiences its body, how its body orientates in space and how that body feels are inherently conflated (Grady, 2005). In a crude sense the somatic or bodily domain is initially identical to the experiential domain. During this period of conflation, associations are automatically formed between these two domains.

Conflation gives rise to *primary metaphor*; the fundamental type of association that arises unconsciously and automatically through everyday experience in a world of material things (Lakoff and Johnson, 1999). These associations are embodied in the neural aspects of the developing brain which can be understood as distinct conceptual domains that pair subjective experience with sensorimotor experience (Grady, 2005). For example, the infant's developing sense of spatial orientation represents one domain. Another domain might represent temperature fluctuation. Both of these are inherently somatic. A conceptual domain, that which is not directly experienced, involves temporality. But as the infant develops the capacity to symbolise via language and play, these domains via metaphoric processes come to stand in for one another in terms of how the world is experienced and conceptualised. For instance, a pile of coins

can literally be seen but ‘time’ cannot. Metaphorisation enables translation between domains albeit in a symbolic manner. This is why in phrases such as ‘you are wasting my time’, time is understood and experienced in terms of a physical commodity that can be diminished (Lakoff and Johnson, 1980).

Lakoff et al’s ideas provide a way of grounding the body and its relation to a physical, material world. Lakoff and Johnson (1980; p.454) suggest that our conceptual system in terms of thought and action is fundamentally metaphorical in nature. If this is the case then metaphor acts as the operating-system through which people understand themselves and their ongoing relation to the material world.

According to Litowitz (2013), metaphors confer iconicity. This is to say that a metaphor illustrates something abstract by means of a tie to a concrete image or thing. In this way, the concept acquires the same sensory immediacy of the thing in itself. In other words, a metaphor unites two conceptual domains, one being abstract and the other being concrete. I therefore envisage the out there getting in here in terms of not inner and outer but as a continuum with the concrete external object at one end and the abstract concept of it at the other. The division between the two is transcended by their metaphorical union. I therefore bracket-off questions about in here and out there because from this perspective they become a matter of convention and a categorising device. Stern (2009; p.81) appears to share this sentiment, albeit from a classical psychoanalytic perspective, noting that:

“... it does not make sense to refer to the world outside our minds, because mind and world are a unity.”

I also note that in psychoanalytic theory, psychic reality is in itself ungraspable (Enckell, 2002). Instead, psychic reality is manifested through representational means, the investigation of which is analogous to understanding metaphors. Enckell also notes that representation is the means of meaning. If that representation is metaphorical then it is within the metaphors themselves that meaning and self-understanding reside. However, Enckell also observes that if thinking is ultimately metaphorical and rooted in somatic processes, these processes have become so naturalised and conventionalised they are not always available for conscious reflection. What this suggests is the need for a sensitive method that can explore ME sufferers’ narratives for subtle metaphoric and metonymic processes because this will enable tracing associations between actants that might otherwise be overlooked.

Beyond this, noticing how ME sufferers use metaphor and metonymy and how actants become displaced is commensurate with a focus on the descriptive surface of actants and how ME is experienced. This is where the psychoanalytic sensibility comes in. Using metaphor and metonymy to trace associations and to suggest associations means that recourse to looking for inner complexity or essential qualities is not necessary and this is in keeping with the ANT premise.

However, as Montana Katz (2011) notes, conceptualisation of an object will often involve segments of several metaphoric processes. Moreover, active metaphoric processes will not be mutually consistent. In simple terms, trying to map how an actant displaces itself across place or time as a simple linear relationship will miss the complexity of how one actant may reflect and be involved in many overlapping metaphoric processes. This needs to be held in mind to avoid oversimplifying the complexity of the relations between people and things, albeit through the lens of metaphor or otherwise.

In summary, this section has outlined how Freud and subsequent theorists have thought about the relationships between body, thought and metaphor and metonymy. I described in basic terms what metaphor and metonymy mean and how they relate to the ANT notion of displacement and how displacement is a point of synthesis between ANT and psychoanalytic ideas that is crucial to my psychosocial framework. Metaphor provides a means of establishing the associations between actants. This is critical to understanding how an actant might be displaced materially, temporally or from place to place. Whilst metaphor can be used to trace actantial associations without the need to look for inner or causal complexity, I concluded this section by alluding to the subtle and complex aspects of metaphor and how oversimplification must be avoided.

4.4 Chapter summary

In this chapter I have discussed central ideas that characterise ANT as a method. I have also considered how critiques of ANT as adopting an apolitical stance have been explored from psychosocial feminist perspectives. This discussion was important because it brings to attention not only that there are alternative approaches to how ANT eschews recourse to *à priori* categorisation and how categorisation can be resisted, but also as a reminder that ME has a history which has at various times and places resulted in the creation of gendered subjectivities and the suppression of the

female voice. It is important that this history in itself is neither sanitised nor reinvented.

Following the actor describes how the researcher notices an actant, observes what actions it is involved in and follows it to discern what other actants it associates with. *Symmetrisation* describes how the researcher does not prioritise the human actor but grants non-human actants equal status in how a network comes together and its overall effect or action; in the case of the ME sufferer this amounts to how they experience the condition and how they perceive its effect on self. *Displacement* describes how an actant moves itself from place to place and in doing so may change its form and how it speaks on behalf of other actants. *Translation* acts as a metaphor to describe the overall process of the researcher engaging with the various actants that become known. As the research process proceeds this involves making associations between actants, describing how they effect each other's capacities and identities such that overall descriptions about a particular experience of ME can be made.

At the core of my methodology is a synthesis between ANT and psychoanalytic ideas. I outlined the Freudian idea of displacement and its resonance with ANT. Because of the contested, confusing and potentially unconscious aspects of ME and how it is experienced, I explained why I look to metaphor and metonymy as a means of noticing and tracing the displacements and associations between disparate actants. Psychoanalytic inspired ideas are important because they ground the relations between body, somatic experience and thinking.

Metaphor translates between different types of thing and between different domains and this is why I use it to trace the relations between actants. This is pertinent for ME, given the indefinite relation between its somatic and psychological aspects which represent two different domains. I differentiate and add to these domains the domains of material objects [sofas, cupboard, people etc.], cognition [thoughts], affects [feelings, emotions], non-human organisms [viruses, bacteria], concepts [ideas, ideologies, beliefs] and environments [places, spaces]. Whilst I acknowledge the potential for overlap between these categories, my suggestion is that by adopting a relational ontology, these different domains attain equal status in terms of their role in how a sufferer experiences ME. They are all therefore implicated in how an ME sufferer constitutes their reality.

The methodological underpinning allows me to encounter and explore the entire aspect of an ME sufferer's world of things and is not restricted to talking about symptomology, antecedent events or the social effects of ME. All these things can be encountered but in a contextualised manner that connects them to each other and focuses on their relations and ME as a dynamic process. I deem this a psychosocial method because of the way in which, by following metaphor, the social, the psychological and the bodily seep into one another and the material world of objects.

The purpose of grounding my research with an ANT-informed methodology was to establish a means of addressing the heterogeneous nature of ME and its hitherto neglected relation to self and the material world, the particular appeal being how ANT adopts a relational ontology between all actants, be they human or otherwise (Latour, 1997). This core premise is crucial to the current investigation of ME. Assuming that each potential actant has equal standing means there is less likelihood of being seduced by existing discourses of ME or interpreting particular things in particular ways that would otherwise lead to reproduction of existing ideas. Considering the entire experience of the sufferer and not just their ME experience provides a better position from which to trace where ME infuses into and out of experience as a whole.

In line with Moser (2006), I view ME is not a category that pre-exists activity but as continually constituted and reconstituted as different elements co-exist and co-interfere. In other words ME inheres:

“...in the particular socio-material arrangement of relations and ordering of practices that simultaneously produce the social, the technological, the embodied, the subjective and the human.” (*ibid.* p.376).

Having outlined out the basis for my methodological premise, chapter five describes the methods I developed and the demographics of the ME sufferers I worked with.

Chapter 5

Methods

5.1 Chapter overview

In the previous chapter I established the methodological basis for my research. The broad thrust of which is to consider how ME affects self experience by synthesising ANT with ideas about metaphor and metonymy. The resulting actor-networks that can be described can provide a descriptive statement about how ME is experienced by a particular sufferer and how that experience is comprised of heterogenous actants in dynamic association with each other. The focus is on the associations between actants, which include the body, home everyday environments, everyday routines and practices, specific material objects and what the sufferer discusses with me. It also includes my affective response to the data and research process. To notice and think about how actants associate with each other and to explore the conscious and unconscious aspects of each sufferer's experience of ME I will employ methods that frame associations metaphorically or metonymically. The present chapter describes these methods. Where appropriate, I refer to my data or other studies to illustrate my methodological choices. I conclude by describing the heterogenous, indeterminate and dynamic characteristics of each sufferer's particular experience of ME in terms of an *assemblage*.

5.2.1 Research design overview

My research aims were to extend existing qualitative work on ME by developing a psychosocial understanding of its effect on self experience.

Longitudinal naturalistic participant observation and partially structured interview methods were used. Data included sufferers' narrative accounts of how ME affects their self experience, consideration of material objects in the home environment that sufferers designated as significant in their day to day lived experience of ME, the daily routines that sufferers engaged in, the environments beyond the home that the sufferer interacted with and my affective response to these strands of data. In terms of daily routines and objects, the focus was on how these were meaningful for the individual ME sufferer.

The research schedule was five visits across six months; enabling snapshots of how self was experienced over time and allowing for ME sufferers to miss and reschedule a research visit if necessary. ME involves a remitting/relapsing course. Previous studies suggest this process results in shifts in how the self is experienced and envisioned across time (Corbin & Strauss, 1987). My assertion was that understanding how self might change in relation to ME could not be achieved with a single research visit.

5.2.2 *Sampling and inclusion criteria*

This research included people aged 18 or over with an existing clinical diagnosis of ME. Self-diagnosis was not sufficient. The implication of *not* having a clinical diagnosis was that the sufferer may have failed to have had a different medical or psychological condition diagnosed that would ultimately lead to a different outcome.

The course of the ME illness trajectory is variable (Fernández et al. 2009). Sufferers with ME at any stage of the trajectory were included, which allowed for a broader understanding of the condition. However, they had to be generally healthy of mind and body to the degree that they were able to take part in the research with no adverse effects. Data collection required ME sufferers to engage in discussion and in their everyday physical activities. This meant that only individuals in the chronic rather than the initial acute stage of the condition came forward or were included. ME symptomology overlaps with other conditions entailing fatigue as primary feature (Mihirshahi & Beirman, 2005). Prospective sufferers taking part therefore required no existing diagnosis of a co-morbid fatigue disorder. Participating ME sufferers had to be able to provide written informed consent before the research proceeded, as an ethical prerequisite.

As ME can affect anyone I aimed for a sample of sufferers that reflected different geographical sites and the entire prospective age range. However, because ME is over-represented by females (Dowsett et al. 1990) I selected a sample balanced for gender. This provided greater potential to think about any particular gendered aspects of the condition that emerged.

As my methodology involved thinking about the particular experience of ME, I did not seek to develop a nomothetic model of the condition. However, the projected sample size of eight sufferers provided a range of experiences. Given the number of encounters with each sufferer and the disparate material being collected, more than

sufficient data was generated. Because the methods involved intense work and the data set was large, working with more ME sufferers would have resulted in an unmanageable amount of material.

5.2.3 *Recruitment*

I initially thought that specialist ME clinics would provide access to sufferers. However, in line with Richman Flaherty and Rospenda (1994), drawing ME sufferers from this setting might reflect only those with access to health care. I opted instead for recruiting from across the community to obtain a broader demographic. I approached MEassociation.org.uk who directed me to local self-help groups. I visited four groups from towns within a forty mile radius of each other in the South West of England and spoke to as many individuals as possible at each group, leaving a summary sheet about my research including ethical considerations and contact details. I was subsequently approached by fourteen individuals and followed these up by phone. I note that recruiting in this manner effectively comprises self-selection, which may result in sample bias. This is not an issue given the nature of the research but requires consideration none the less.

5.2.4 *ME sufferers taking part and demographics*

As data collection proceeded, I wrote short pen portraits summarising the life experiences, experiences of ME and general background history for each sufferer and referred to these throughout the analytic process; see appendix 11; note that Carol is not included as she withdrew from the study. These portraits aided holding in mind each person and their context. Each sufferer chose their own pseudonym to ensure anonymity. The following table (1) lists the characteristics of sufferers who started the research process:

ME sufferer pseudonym:	Gender:	Age (years):	Year of ME diagnosis¹³:
Bruce	Male	57	2007
Carol	Female	63	2003 [withdrew from study]
Hannah	Female	25	2004
John	Male	49	2005
Freya	Female	43	2010

¹³ Date of diagnosis does not reflect illness duration; all sufferers described ME antecedents predating diagnosis. Data collection began in July 2011 and was completed in February 2012.

Les	Male	65	2005
Patsy	Female	54	2008
Whimsy	Female	59	2002

Whilst all sufferers had received a formal diagnosis from a specialist clinic, it was not possible to establish the specific diagnostic criteria used.

5.2.5 *Ethical considerations*

Prior to recruitment, ethical approval was obtained from the University of Bath Psychology ethics committee. I also consulted and adhered to the British Psychological Society's guidelines for ethical research (BPS, 2009). My primary concern was that the methods might induce difficult feelings or knowledge that the sufferers had not previously experienced. From the outset, sufferers were made aware of this potential via clear discussion of the research protocol, answering their questions and a printed information sheet which they retained [appendix 1]. The research commenced when sufferers had been read the briefing sheet [appendix 2] and signed a written consent form [appendix 3].

I acknowledged two specific ethical issues that may have arisen, in light of BPS ethical guidelines 3.1:

3.1(i) The study involved being alone in the home of/with potentially vulnerable individuals. I was therefore mindful of potential risks of physical harm to myself from the environment or the sufferer for the duration of the study period.

3.1(iv) Each visit represented a potential intrusion into the everyday secure environment of the ME sufferer and therefore needed to be one of respect and integrity where the researcher 'listened' to sufferers in a non-evaluative manner.

Further areas of consideration were: *anonymity*, *confidentiality*, *right to withdrawal* and opportunity for *debriefing*. At no time were ME sufferers taking part identifiable by name or person. They were assured that all data relating to them would be reviewed by the researcher alone. This was important given the extent of audio/visual material by which they might be identified as well as idiosyncratic objects, environments, routines and the highly sensitive nature of ME. Video captures used in the written report avoided showing individuals but were selected to illustrate the idiosyncratic

nature of their objects, for which permission was obtained. Audio-visual data was encrypted and stored on an external hard drive kept in a locked cupboard in the researcher's house, as were written notes and recordings. The ME sufferers taking part had access to the researcher's contact details and those of the lead supervisor. They were aware that they could withdraw at any time from the research without justification. One sufferer did request withdrawal by phone after my second visit. Prior to the final research visit, sufferers were mailed a questionnaire to complete. This included all symptoms that might comprise their ME profile and space to reflect on the research [appendix 4]. It provided a tangible end for them, whilst ensuring that I had correctly understood and recorded their symptoms. The questionnaire was discussed with each ME sufferer. They were then read the standard debrief [appendix 5].

During debriefing, three sufferers informed me that they had benefitted greatly from participation. They welcomed the opportunity to talk at length and explore their experience of ME. They explained that they felt that the research process had somehow improved their symptoms and understanding of their ME.

5.2.6 *Data and collection methods*

I wanted the data to include anything that might comprise an individual's ongoing everyday experience with ME and my participation in that experience. With ethnographic methods in mind I aimed to enter into the sufferer's everyday life and what they would normally encounter. This enabled me to become an actant in the networks in which the ME sufferer was entangled and meant that I had to find ways of holding onto disparate strands of that experience, such as feeling, hearing, seeing, participating, talking and thinking.

My involvement in the ME sufferers' daily routines represents participant observation and allowed me to understand the experience of ME and its effects via an open dialogue that lead to a shared understanding (Huspek, 1994). However, I note that the term participant observation may connote that one can observe a setting from an objective viewpoint and that the setting exists as a bounded object. This would be desirable from a naturalistic perspective (Hammersley & Atkinson, 2007). However, the psychosocial framework to my approach is inherently reflexive. The implication is that whilst I attempted to maintain a realist position in that there clearly exist ME sufferers living lives that go un-researched, the moment I enter into those lives means

that my descriptions of ME are inevitably a product of my interpretive stance and personal history (Bourgois, 1996). This is clearly the case, given that a part of the process involved interpreting my affective response to participation and discussing it with the sufferers.

I used methods that enabled me to record as much of the experience as possible. Below, I outline the data and my rationale, but it should be noted that data types clearly overlap. All of my visits, discussions and participation were recorded on a digital video camera, with a built in microphone providing an audio-visual record to refer to. My initial visit with sufferers was based around a partially structured interview which enabled a reflective understanding of experience. The decision to use an initial partially structured interview addresses some important issues.

According to Lucey, Walkerdine and Melody (2001), interviewees accounts are neither value nor emotion free. Interviewees seldom conform to the model assumed by some sociological approaches where they are conceived as fully rational and in charge of their emotions. Instead, the interviewee/interviewer relationship is founded on unconscious, intrapsychic processes which necessitate both parties defending against unconscious anxiety and feelings that the interview arouses. Drawing on one's own feelings and exploring them in relation to unconscious processes, both intra and interpsychic, and anxiety characterises a particular approach to psychosocial research, such as that developed by Walkerdine, Melody and Lucey and this intersects with other feminist orientated methods. Hunter's (2005) feminist inspired psychosocial work, which highlights the complexity of exploring the voices of individuals in positions of power in relation to health and social care services and the social relations of gender and ethnicity, is useful in this light. It brings to attention how the 'voice' of participants in a research setting mediates between identity and experience in dynamic ways. At the heart of the research relationship are power differences such that assuming the interviewee to be a 'good story teller' and the interviewer a 'good listener' amounts to an oversimplification.

What I take away from these works is that even a pragmatic choice, such as what form an interview takes, should be carefully considered. Attention should be paid to the intrapsychic and inter subjective play of emotion, power and the ethical field that these are situated in as part of the research process. For example, Hunter notes that on one hand, closed questioning and structured approaches provide participants with the

opportunity to label themselves and to explore the meanings of these labels. Questions can also be constructed to uncover or challenge silenced or unacknowledged gendered or racialised power, for example. I also imagine that structured approaches emplace a scaffold which mitigates some of the anxiety that might be mobilised in both parties. On the other hand, a less structured approach, perhaps with open questions, enables participants to respond in ways that reflects their particular unconscious defences. This can be useful because it foreshadows how the act of communicating is always negotiated, potentially conflicted and relational. This is where a psychoanalytically informed means of ‘listening’ and using one’s felt response to the interaction can itself be interpretative. However, it also implies the ethical requirement, on the part of the researcher at least, to acknowledge their own [potentially] ambivalent responses, resistances and silence to the unconscious plays of power in what amounts to a social process.

Because I had to trace associations within and across data sets and look to the affective response of the researcher a conversational approach was adopted (Rubin & Rubin, 1995). This allowed for the pursuit of unexpected turns in the narrative and following up affectively informed ad-hoc and post-hoc interpretations.¹⁴ The rationale of adopting a conversational style was to engage the ME sufferer in their everyday world in an emic sense (Kottak, 2006). With ethnographic methods in mind, my approach reflects the idea that an interview is “a shared conversation through which new ways of knowing are produced” (Pink, 2011; p.271).

Given my focus on the relation of ME to material objects and places, it was important to explore the full range of what I saw. Thus, how the sufferer gestured, shifted their body, how they interacted with material objects in the environment and how objects appeared to me all constituted visual data. Given my methodological rationale, visual data provided a means of tracing the associations between people and material things/places. Moreover, the use of visual material reflects the notion that:

“Meanings are made in situ through the full spectrum of sensory phenomena with which actors engage [...] but also reverberate within webs of signifiers” (Hurdley & Dicks, 2011; p.278).

¹⁴ My interview style was influenced by biographical narrative approaches and eliciting statements about experience; see for example Bury (1982; 2001), Williams (1984), Wengraf (2001).

According to Tilley (2006), creating and using objects is a function of the social persona and Elias (1987) notes that splitting subjects from objects is misleading because it suggests one can exist without the other. It was therefore important to experience the relationships between people and things.

Visual media not only record what people say or do but also materially instantiates and connotes relationships that may not immediately be apparent, because they become part of the practice or process of the research itself. I therefore note the reflexive relationship between the ANT notion of how actants effect each other's actions and identities and the media I used to record the research visits. This makes explicit that the modes and media I use are as implicated in the research process as I am. As Pink (2007; p. 243) puts it, walking and talking and recording the interaction with a video camera

“Afforded me the opportunity to use my own sensory embodied experience as a basis from which to empathise with others.”

Using a video camera allowed me to record conversation and the visual scene at all times. I became proficient in participating and chatting with sufferers whilst automatically being able to shift the camera to record and capture scenes as necessary. For instance, throughout visits where my participation was involved, such as cooking or going to the shops, I used the video camera hand-held to track the general scene as well as to record conversation. During the initial semi-structured interview, the camera was set on a tripod to record myself and the ME sufferer in conversation. In this way I could follow up shifts in position and non-verbal cues on both our parts and match these with the affective data from my Dictaphone or notes.

In my participatory visits such as walking to the shops, conversation also took place and this reflects the blurring of the line between interviewing and participating (Hammersley & Atkinson, 2007). More significantly it reflects recent anthropologically orientated researchers who discusses how participation involves all the senses as well as the body and as such can be thought of as a phenomenology of perception and hence interpretation. This means that perception is an holistic state that is mediated by the socio-cultural background and immediate context.

Harris (2007; p.4) states that that:

“Knowing is continuous and processual, it is situated and it is bound up with human engagement, participation and movement”.

The implication is that there is something different about sitting and talking with someone and walking, talking and participating with them in different contexts. Without negating talking alone, participating by walking and talking provides an opportunity for a different type of affective engagement and hence different knowledge. This resonates with Ingold’s (2004) criticism that much academic work has prioritised the visual over the other senses and that embodied participation provides a different perception of surroundings and experience.

A most important feature of my research and one that contributes to my psychosocial framework is the way in which I managed to participate in the everyday experiences of ME sufferers and the things they did to manage their ME and sense of self. According to Smith (2014), existing health research rarely goes beyond interviews and to actually get into someone’s home, routines and life on five occasions over an extended period is quite unusual. Constantly using my affective response to notice and engage in an authentic manner meant that I was able to go beyond focussing just on ME and this put me in a privileged position to understand the entanglements between ME and ‘not-ME’.

5.2.7 *Affect and its importance as data*

A psychoanalytic notion of *affect* is central to my methodological rationale because I assert that interpretation and description of a state of affairs always entails an affective component. Affect is thus implicated as part of the communicative process.

In line with Orange (1995) and in terms of intersubjectivity as outlined in chapter three, I denote affect as an undifferentiated somatic response that ordinarily develops by desomatization, articulation and differentiation. This speaks of the awareness of one’s own feeling state and also recognising that of the other. The interaction between two or more people involves the transference and sharing of feeling and emotion [the affective state] through the mutual generation of the intersubjective field created around and between them (Ermann, 2012). It is in this intersubjective affective space that emotion is organised and made meaningful.

Orange (1995) asserts that many methods used in research, such as questionnaires and interview schedules, provide a sense of security and a safe emotional distance from the participant and one's own emotional response. Law (2004) echoes this sentiment. But the price paid is explanation at the expense of understanding and that no method or technique will yield understanding. Instead, affective engagement with the other allows empathic understanding to emerge in a reflexive sense. This stance informed all of my interactions with the ME sufferers I worked with. Central to each visit from the outset was to establish rapport with the ME sufferer and engender a relationship of trust. This comprises part of the affective aspects of the process. It was crucial to identify my own affective processes as well as those of the ME sufferers I worked with. These included tolerance of affects and making appropriate responses (Lech, Andersson and Holmqvist, 2008). It was also important to maintain active listening (Wengraf, 2001) because a failure of active listening may curtail the sufferers' engagement and lead to attenuated talk.

Participation involved an affective response to the ME sufferer, the places they took me and their objects. This mirrors the everyday setting of social interaction. One's affective response is inherently embodied and sensorial (Pink, 2008; 2010). Pink alludes to the idea that sharing an experience and hence an affective state can lead to moments of insight about the other's values and meanings. I used this notion to reflect my feelings and thoughts back to the participant in a conversational and relational manner. Reflexively, this can be understood in terms of how my understanding was fed back into analysis and whether it enabled new associations and inferences to be made. The process of feeding my affective responses and thoughts back to the sufferer took place at the start of each subsequent visit and thus informed following the actor in the ANT spirit.

Because one's affective response is emergent, pre-reflective and pre-verbal it cannot be predicted. Rather than disrupt participation by stopping to write field notes, if I felt an affective shift or if I believed that I noted an affective shift in the sufferer, I marked such moments on the camera by saying "oh I must remember that" or similar. Immediately after each visit I sat in my car and recorded my reflections on Dictaphone and wrote down key words or specific actants that I felt needed following in my field journal, in a subjective way (Wolfinger, 2002) that aimed to capture my affective response.

Whilst some forms of data such as actual audio-visual material and objects are more concrete than affective data, how one responds to what is seen or heard always involves an affective element. However, it is not always clear why one feels what one feels and hence what mobilises given affects. This is why psychoanalytic ideas and the notion of unconscious processes beyond what initially appears as rational are important.

5.2.8 *Schedule and structure of research encounters*

Each research visit entailed a specific focus with the aim of exploring various aspects of the ongoing experience of ME. The first and second visits occurred in the sufferers' home. For visits three and four some ME sufferers took me to other sites [table 2 below].

Visit 1 involved meeting the ME sufferer, briefing them and obtaining written consent to fulfil ethical requirements. I then used a narrative interview, beginning with the question "Tell me about your life history" and later "Tell me about your experience of ME"; designed to elicit discussion of relationships, work, family, problems, education, medical and developmental history (Dayle-Jones, 2010). The question order aimed to avoid prioritising ME as defining the sufferer's broad experience. The nature of the interview was such that answer categories were not pre-determined to avoid closure of topic area (Minichiello & Stynes, 1995) and was suitable as a natural extension of participant observation (Patton, 1990) which was employed to enable me to respond affectively to the sufferer's experience and to aid tracing associations between actants. Between each visit I transcribed my affective notes and audio-visual data and reflected on each ME sufferer. This allowed for my ongoing affective responses to form. In fact, during the research period I was able to focus on little else because the sufferers I worked with and their experiences with ME were constantly in my thoughts and feelings.

Visit 2 began with follow-up questions from the previous visit concerning my affective response and observations. It enabled me to 'follow the actor' (Latour, 2005) and trace associations between emerging actants. I then proceeded with a focussed discussion of the sufferer's home environment and self-selected significant objects. This allowed me to identify key material actants and environmental aspects and how the participant understood these in relation to their ME experience and their meaning for self. I often

asked the sufferer if I could handle or use material objects so that I experienced a direct response to them. During this visit I also took the opportunity to notice other artefacts that the sufferer might not have mentioned explicitly. In this way I developed a feel for each sufferer's home and the things in it.

Visit 3 proceeded as before with follow-up questions. I then employed participant observation of an activity in the daily routine of, and chosen by, the sufferer. This enabled a focus on the lived experience of ME in terms of how daily routines are structured into self experience, so that ME could be explored as instantiated through practice and activity. Activities were framed and explored as an actant as this enabled me to connect them to other actants and made following my notes and interpretations easier to manage. I never knew what to expect before these visits and I anticipated each one with a high degree of excitement.

Visit 4 began with follow up questions. I then used participant observation of an activity chosen by the participant that was not necessarily in their daily routine. The rationale was that the specific choice of activity would enable the extension of associations with broader actants as well as associating with significant features of broader self experience and understanding. There was however an unavoidable demand characteristic in effect because I had asked each sufferer to choose to do something meaningful for them. They had to choose something. However, what sufferers chose not only surprised me but invariably mobilised a range of affective responses from empathy, excitement, boredom, trepidation and so on. Despite the risk of sufferers responding to the demand characteristics of my method, my analytical framework revealed that what each sufferer chose was meaningful for them and fitted with their general experience of ME.

Visit 5 proceeded with follow up questions. A semi-structured interview then allowed me to elicit reflections of how ME had been experienced across the six month study period along with any changes to self experience and self-understanding the sufferer had experienced. I then used the tick list [appendix 4] as detailed above. The final visit concluded with the opportunity for the sufferer to ask me any final questions and reflect on the process and then a full debrief to fulfil ethical requirements [appendix 5].

The following table (2) outlines key aspects of what each ME sufferer selected as objects or visit focus. Only the most significant material actants are listed to give an

idea of the variation of what was selected. Visits ranged in time from 45 minutes to 111 minutes with a mean duration of 64 minutes:

Participant	Visit 1: History/ ME experience	Visit 2: Environment/ material actants	Visit 3: Daily routines	Visit 4: Chosen activity	Visit 5: Reflecting/ debrief
Bruce	History/ ME experience	Work bench, food blender, juicer, cupboard	Blending fruit smoothies	Dinner for me and Bruce	Debrief etc.
Carol	History/ ME experience	Bicycle, guitar	Participant requested withdrawal		
Hannah	History/ ME experience	Hat, soft elephant, paintings	Wii fit	Talking about and showing me paintings	Debrief etc.
John	History/ ME experience	Paper (letters, documents, flyers etc) books...	Walking to town	Creative writing	Debrief etc.
Freya	History/ ME experience	Sideboard, boots, violin	Cleaning out the rabbits	Comparing experiences with others sufferers	Debrief etc.
Les	History/ ME experience	Music centre, audio books	Getting the shopping	Visit to the cemetery	Debrief etc.
Patsy	History/ ME experience	Violin, bird - book, camera, caravan, bicycle	Walking on the hills	Knitting	Debrief etc.
Whimsy	History/ ME experience	Peg-in-case, writing front sheet, statue	Meditation	Comparing experiences with other sufferers	Debrief etc.

A question arising from qualitative work, especially IPA, concerns the interpretative role of the researcher which, according to Brocki and Wearden (2006), is often not made explicit. This issue intersects with the question of whether interpreting ME requires a specific theoretical framework. A lack of a specific theoretical position may result in ungrounded analyses. If a theoretical frame is too rigorously applied then there is a risk of decontextualising the data and losing sight of the whole case. To address these issues as a whole requires developing methods that makes explicit the interpretive role of the researcher but from a position of subjectivity where the experience of another person [with ME] can be felt and responded to without an inflexible theoretical framework. Rather than develop methods that establish *á priori* what, for instance, fatigue is likely to mean for the sufferer, it would be beneficial to explore how such symptoms reflect particular associations between the body, discourse and materiality and are meaningful to *particular* sufferers.

A psychosocial approach is ideally suited to developing a reflexive stance to research, given its psychoanalytic influences and concern with the researcher's affective engagement and the potential for unconscious conflicted states (Clarke & Hoggett, 2009). Part of this is to get beyond one's biases and the lure of creating an objective account of the research. Reflexivity speaks of the need to defamiliarise the familiar and to resist accepted yet unwarranted understanding. Adopting an explicit awareness of the affective field around the researcher and participant is one way of approaching this. If the researcher acknowledges their subjective relation to the research process they are open to the possibility of multiple understandings that can only be resolved by avoiding foreclosure of the analysis. Iteratively checking and updating their understanding as new information and experiences occur allows ideas to form and fade and new ones to emerge organically as the data unfolds with the researcher. This may not occur if the researcher ignores their affective state and instead prioritises the intellect and actively seeks out answers and conclusions (Crociani-Windland, 2009).

Acknowledgement of researcher subjectivity and the need for a reflexive stance have been central to qualitative research for some time and direct us to "...legitimize, validate, and question research practices and representations' (Pillow 2003; p.175). However, there is a danger of rubber-stamping research as reflexive without considering its epistemological role. This necessitates consideration of the

methodological rationale in terms of its realist or naturalist stance, especially in terms of ethnographic research (Hammersley & Atkinson, 2007). For this reason, a further aspect of the methodology I developed was to account for my role as researcher and hence a reflexive stance as integral to the research process *and* the theoretical framework. ANT lent itself to this position because, as Latour (2007) states, I was obliged to resist the tendency to invest things with familiarity and to accept that the phenomena of research were resistant to an absolute representation. I had to acknowledge the transient nature of understanding and especially interpretation. This became even more acute in light of the affective aspects of the data and that I was enfranchised into the ME sufferer's actor-networks. From that position each statement, affective state and emergent understanding always had the potential to effect further and different associations with new actants. The process was inherently reflexive.

However, I also note that it is impossible to ever be fully cognizant of one's affects, let alone those of others. The act of empathising, attunement and interpretation always occurs in a mediated manner. Thus, making affective sense of a person's life history, how they experience ME and how these relate to particular objects and environments is a complex, psychosocial process. As noted by, Walkerdine, Lucey and Melody (2001; p.84):

“A researcher in the social sciences is not simply presented with objective data, she is also presented with a number of narratives. These narratives are often emotionally charged, and always meaningful to the subjects.”

Thus, interpretation does not give “greater proximity to the truth”. (*ibid.*) and often reflects the researcher's own history.

To that end, I found that having regular supervision was crucial because it allowed me to reflect on my analyses and alternative interpretations. This meant that I had to work harder to substantiate my analyses and this made them more robust.

5.3 Analytic strategy

In this section I outline the approach to each research visit, how the visit was managed, what was done with the data and how the data was drawn together into descriptions of the experience of ME on self. Because of the method-theory status of ANT, I do not differentiate analysis as a separate procedure. To suggest that analysis can occur separately from the process of the research diminishes the reflexive stance of the

researcher who is in fact an actant in the network (Law, 1999). Analysis was considered as occurring from the outset. Similarly, because of the contingency of actor-networks, I offer not a definitive account of the experience of ME and its effect on self but some descriptive observations that reflect the way that actants associated in given places and times for particular ME sufferers. My aim with this statement is to emphasise the fluidity and particularity of each experience of ME and that understanding ME implicates one's own subjectivity, including that of the reader of this thesis. In terms of reflexivity, this lead me to avoid thinking in advance that I knew what the actors were really saying and imposing my explanations of their terms on them (Latour, 2005). Formal analysis of each research encounter initially followed a thematic approach (Harper & Thompson, 2011). Iterative reviewing of each transcript and sequential transcripts in conjunction lead to broad overlapping themes which were left open and unrefined to avoid closure in relation to uncollected data. Core analysis involved tracing the displacements and associations between actants by identifying the metaphorical or metonymical equivalence between them and within and between different domains¹⁵. For instance, from Les's data set the metaphorical displacement of the actant 'chest pain' [physiological and psychological domain] was traced to a particular place and objects; cemetery and gravestones, [material domain]. Overall translation of actants and the gross character of how actants came together as a network were built up in this manner.

5.3.1 *Procedure for each encounter*

The procedure for each, visit beyond brief/debrief, was:

- Establish rapport using vocal intonation, empathic listening, displayed interest, authentic conversation and body language. Hold in mind the purpose of the research and each specific visit.
- Ensure the sufferer was clear on the purpose.
- Ask relevant follow up questions [second visit onwards].
- Record all interactions using digital video camera [tripod/hand-held as necessary]
- At the end of the visit, ensure the sufferer was not in a negative state; arrange the subsequent visit.

¹⁵ See chapter 4 (4.3).

- Sit in my car and record immediate affective response on a Dictaphone, including things to follow up.
- On returning home type up recorded response and add to it as necessary. This constitutes *initial affective response* [appendix 6 for exemplar].
- At the first opportunity, review the video material and write up affective responses that emerged. This constitutes *affective response to video* [appendix 7 for exemplar].

5.3.2 *Transcription*

The next stage was to personally transcribe the video recording of every visit. This was necessary because establishing myself as an actant in the sufferer's network entailed that my responses and actions at all stages were available to me. Given the psychoanalytic influences to the methodology, I attempted to capture the idiosyncratic aspects of the discussions in terms of pauses and laughter and to match these with shifts in body position and other non-verbal cues. To record these non-verbal responses I use parentheses with pause length in them and the Microsoft Word review facility to add running comments alongside each line of transcript as necessary. Each transcript thus comprised of talk annotated with non-verbal information and any affective response that emerged in-process [appendix 8 for exemplar transcript section].

5.3.3 *Initial thematic analysis and coding*

In this section I outline the use of thematic analysis (TA) and why it was suitable for the initial organisation of my data.

Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). Whitehead (2004) suggests that it is artificial to divide analysis into thematic analyses and categorisation. Cassell and Symon (1994) state there is no distinction between analysis and data collection. These points resonate with my use of ANT as discussed. The choice of TA for the initial stage of analysis was the way it correlated with the process of entering a network and noticing actants and their associations.

However, an important question that frames TA is what constitutes a theme. Braun & Clarke (2006) state that a theme captures something important about the data in relation to the research question and represents a patterned response or meaning within

the data set. My approach is slightly different in that I bracketed off the research questions and entered the network with as few preconceptions about ME as possible. What emerged as a theme represented a pattern that didn't only rely on semantic continuity and similarity between statements. Instead, I began formal analysis with iterative reading and immersion in all my data for a given sufferer and allowed myself to notice instances that appeared to associate with each other and annotated copies of the transcript with thoughts, highlighting salient points and cross references between pages. I relied on using the ANT premise of translation to think about how two things might associate into a theme in a displaced form and also held in mind the potential for metaphoric and metonymic relations albeit in a loose sense. The notion of the actant had to remain in focus at all times.

Coding began when I felt that the initial stage had exhausted itself. I then began to link key annotations under a category label. I moved slowly through each transcript annotating with coded labels; such as these codes from Les' data set: HS (Head symptoms), IA (Issues with authority) and CI (Country as an ideal). I took codes forward to subsequent transcripts to interrogate for further instances. The iterative process of thematising and coding thus occurred within and across transcripts for each sufferer. Finally, after each transcript had been thematised, I went back over each other transcript to investigate whether instances of codes from later transcripts appeared in earlier ones. This allowed me to gather looser themes together into one place and to re-label some themes in a more suitable manner [appendix 9 for exemplar]. During this process I also made notes that indicated possible interpretations and ideas.

The issue of interpretation is salient regards my methodology. By maintaining the ANT spirit of letting actants describe themselves without recourse to inner complexity, what I was doing was noticing how things associated and what actions and identities resulted. However, some interpretation of the associations between actants was unavoidable, but this didn't require looking inside each actant to find some latent causal complexity.¹⁶

¹⁶ For discussion of problems involving interpretation and the *manifest* or *latent* nature of themes see Patton, (1990); Boyatzis (1998); Braun & Clark, (2006).

Having discussed the initial familiarisation and organisation of the data in light of TA, in this section I describe the movement from theme to actant.

To recap, an actant is an entity that in association with other entities defines and has defined its identities and actions (Ritzer, 2004). An actant's agency is taken as 'relational and non-volitional' (Pels, Hetherington and Vandenberghe, 2002). Within this definition is a tension represented by the notion of a discrete entity with no inner complexity or essence that is influenced by and acts only via its networked associations and the problem of how to notice such an entity, if it only exists in terms of its relations in the first place. Callon (1998) notes a danger in presupposing that something is an actant and that it is difficult to establish how a discrete entity exists in the first place, unless the criticism is invoked that nothing exists beyond the network. This is to say that ultimately, no object or concept exists except in relation to something else.

Given that an aim of ANT is to restore materiality to analyses of society and technology, there exists a second tension in that some actants are material whereas others are social or psychological. However, the ANT emphasis on relations rather than entities *per se* represents a paradox because the types of actants just described transcend simple categorisation as well as not existing as a discrete entity in the first place.

To overcome this paradox I suspended thinking about actants as members of psychological, social, material or conceptual categories. Instead I held in mind their relationality, how they effected each other's identities and that the premise of my methodology was to overcome the dualistic thinking that categories presuppose. Further consideration of these issues is warranted but is beyond the remit of this thesis.

To compare the notion of actant with that of theme was necessary. Ely et al. (1997) suggest that a theme resides not in the data but in the researcher's head and results from thinking about the data and creating links as they come to understand it. Themes and coding represent a somewhat arbitrary categorisation process that, whilst subjective, also reflects specific epistemologies. Some of these issues apply to the manner in which an ANT analysis would identify and associate actants. Overall I feel that whilst I have tried to develop a systematic methodology, the subjective element

and the ongoing presence of the researcher will always render some descriptive and analytical choices as idiosyncratic. This is also an area that requires further consideration.

Beyond this, I ascribed some basic difference between themes and actants that enabled me to move from the former to the latter. Firstly, material actants represent entities that are more bounded than a theme. They exist beyond the researcher and already carry out a function prior to being noticed. As themes are developed early on in the data it should be apparent that some material objects are acting actantially. In other words they don't necessarily appear at one site only but instead can be traced in a displaced form or have other actants constellating around them. Establishing whether a material object acted in a mediating sense involved checking how many times it appeared, the intensity and quantity of its associations and the affective significance of it for the sufferer and myself.

Establishing non-material actants was more difficult. The scale of what can be theorised as a non-material actant and the epistemological questions this raises is beyond the remit of this theses.¹⁷ I emphasise the manner in which any descriptor, such as 'cosmopolitanism' or 'anxiety', is itself actantial in that it can displace itself or appear at different sites in association with different actants. Therefore, non-material actants have a life of their own but always and only through their associations. To move towards describing an aspect of my data as a non-material actant was based on a concept that was initially a theme and:

- Appeared at multiple sites in an explicit form.
- Appeared at multiple sites in a displaced form that didn't rely on recoding it.
- Appeared to act in a mediating sense in that other actants associated with it.
- Appeared to possess a specific identity in association with the sufferer.

An example of a non-material actant from Patsy's data set would be *rhythm*. This appeared implicitly in early transcripts and explicitly in the third and fourth. Patsy explains that one can use rhythm as a 'conscious contemplation thing' or 'just to be in

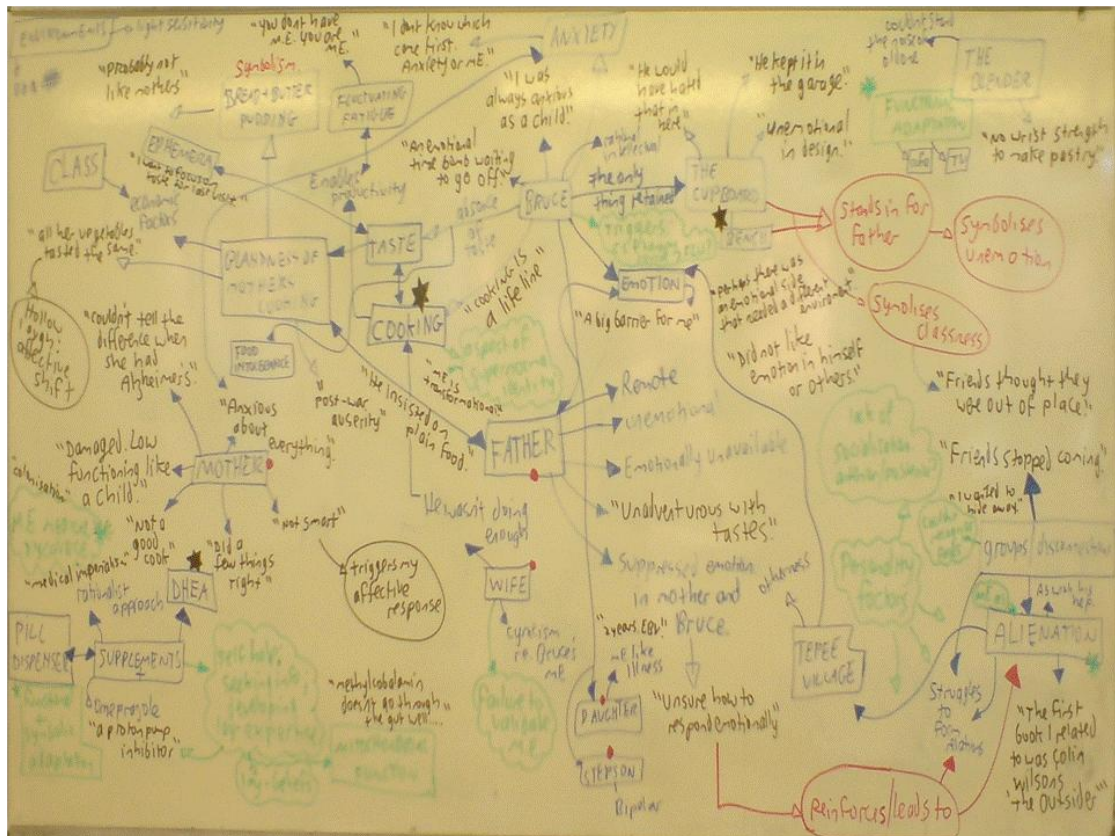
¹⁷ Specific examples of ANT studies that define specific non-material actants and which suggest the potential for different scales of actant are 'cosmopolitanism' (Saito, 2011), 'institutional logics' (Tryggestad & Georg, 2011), 'learning identity' (Aberton, 2012) and 'climate change rhetoric' (Besel, 2012). In these analyses, many material and other non-material actants are implicated and there is also the issue of the conflation of scale with geographical space (Collinge, 2006).

the moment'. At times she explains that rhythm is 'clashing and out of sequence'. Whilst she is out in 'nature', walking, Patsy was aware of the rise and fall of her breath, her bodily movement, pace and their relation to the ground. She felt 'better walking in the fields' and not roads because there was more literal contact with nature and also because the 'vibrations' that came up from the ground were naturally rhythmic. When Patsy knitted she also recognised the rhythm of the process and this was also the case with her fiddle-playing. Both knitting and the fiddle are actants. Crucially, rhythm associated with ME for Patsy because ME enforced a slower rhythm on things and this was 'not something she would do naturally'. Conversely, Patsy used other actants to moderate and mediate her ME. She paced herself in terms of monitoring the rhythm of cycling, walking, fiddling and knitting. ME had intensified her need to feel and maintain rhythm but her awareness of her personal rhythm and its relation to being outside predated ME and interestingly rhythm also represented an 'almost private space'. Patsy also recognised the importance of seasonal rhythms in 'nature'. Overall, this example illustrates in a crude way how rhythm was an actant that informed Patsy's ME experience and was also part of her ongoing self-understanding.

Having outlined how I established something as an actant, the following section outlines how I used ideas about metaphor and metonymy to think about the way in which actants associated with each other.

5.3.5 *Using metaphor and metonymy to trace displacement of actants*

Having identified actants, the next task was to trace their associations. This was not easy and to some inevitable extent relied on my subjective understanding of metaphor. To aid the process I initially attempted to visualise the nature of a network. I began mapping out actants on a large wall-mounted white board using different colours to distinguish the concepts I was holding in mind. I added quotes from the sufferer's transcripts and instances of affective responses. The end result of this process provided a tangible way of holding and bringing to mind how salient actants were beginning to associate. An example of this method is given below in photograph 1 (visualisation of initial actants in association from Bruce's data):



The problem inherent in visualising an actor-network¹⁸ is partly why I tried to rethink the network in terms of assemblages. Thus, visual representation on the white board provided a useful organising tool but consideration of the relationship between how this mode of visualisation influences how an actor network is conceptualised requires further work.

After visualising emergent actant associations I began to think about metaphorical relationships. Mueller (2010) notes that analysis of creative metaphors relies on a subjective evaluation based on a poorly defined concept. Metaphor analysis requires a creative, synthesising approach that is dependent on personal factors (Schmitt, 2005). This exacerbates that metaphorisation reflects complex processes and cannot be assumed to reflect a simple mapping of an idea in one domain to that in another (Kimmel, 2010).

¹⁸ Hartt (2013) notes that an ANT analysis is visual in nature to the extent that it can be conceptualised in terms of web drawings or flow diagrams. However, Hartt goes on to note that the complexity of an actor network does not lend itself to visual representation because the nature of associations are multi-dimensional and non-linear.

To approach the issues around metaphor and metonymy I reviewed ways of systematising metaphor analysis. Schmitt (2005; p.368) for instance states that:

“Systematic models of metaphor analysis attempt to reconstruct models of thought, language and action”.

This did not reflect my methodological premise. However, Schmitt asserts that adherence to methodology is less important than aesthetic subjectivity. I read this as the need to appreciate the particular use of metaphor by an individual in conjunction with a reflexive appreciation on the part of the researcher. This led me to conclude that I might be able to develop a framework that acted in a reflexive, heuristic manner. The process evolved as the analysis proceeded and as I gained experience with it. This reflects a further element of reflexivity. Unlike Schmitt I did not set out by specifying a topic area or particular deployment of metaphor in the first place. Instead, I looked to embrace the particular and subjective nature of metaphor and assumed this would include the broad spectrum of the functional deployment of conventional and creative metaphor by ME sufferers to explain their experience of ME to me and to explain ME and understand it for themselves.

To this end I took elements of Mueller’s (2005) systematic approach in conjunction with my psychosocial framework, adopting the following criteria for transcripts and written material:

- After immersion in and thematisation of the data, the identification of actants and for anything appearing metaphorical, I considered the immediate textual context [transcript] as this may suggest a metaphoric or metonymic process, given that metaphors interact with other metaphors (Goatly, 1997; Heywood, Semino and Short, 2002; Benczes, 2011).
- Metaphors may appear salient because of their role in an overall text. I scrutinised the text for shifts in topic, temporality and tense.
- Contextual information may suggest a metaphor, such as a conventional metaphor, triggered by a specific topic. I utilised this by paying attention to the appearance of conventional metaphors or specific topics arising from the ME literature such as ‘delegitimation’, ‘diagnosis’, ‘symptom exacerbation’ and ‘before and after’ narratives (Arroll & Howard, 2013). For example, a metaphoric relation to ‘diagnosis’ might be that the ME sufferer may refer to having to ‘fight’ for the condition to be recognised.

- In conceptual terms, creative metaphorisation may appear when ideas in one domain are being described in relation to a different domain. I scrutinised the data for instances of dualisms where the sufferer explicitly talked for instance about mind in conjunction with body or psychological versus social aspects of ME.

These analytical tools do not describe an exact procedure of metaphor identification nor are they clearly differentiated from each other. They represent a way of noticing and grouping information, as information from all levels may be important to assess the creativity of a metaphor and what it is doing.

Because I established myself as part of the actor-network of the ME sufferer I also had to pay attention to the metaphors and metonyms I used during our discussion and looked to my affective responses to think about how these were received and how they were structured into the interaction. This was particularly important in informing my response to objects and places and their potential for metaphoric and metonymic function. This can be illustrated with a brief example from John's data set. It should be noted that whilst this provides a flavour of my analytical use of metaphor and displacement, chapters six to eight provides the substantial, in-depth analysis of data relating to three separate ME sufferers I worked with.

John (JB) had explained across several visits that he had an affinity with a specific cinema in his home town, which he visited 'two or three times a week'. As part of his daily routine, he took me on his route through the town centre and explained how he always chose a route to avoid 'battling' through crowds. This conventional metaphor is commensurate with his battle against ME and reflects issues with delegitimation (Dumit, 2006; Travers & Lawler, 2008) and perhaps a sense of social alienation. Psychosocially, this metaphor can be thought of as conveying the unconscious hostility and sense of otherness involved in suffering ME and connotes the association between self and other. I noticed on this route that we passed the cinema and paused to reflect this to John, as illustrated in the following extract:

- 1 JF: I'll just get a shot of it. (>3.0) Have you been here recently to see a film?
- 2 JB: Yes. A couple of times last week.
- 3 JF: So what sense do you get then when you come down here?
- 4 JB: There's a sense of kind of warmth and fondness and affection and I know the
- 5 people. They say hi. And they're friendly. And again as I think I said before ()
- 6 just that sense of being cocooned and and () forgetting everything else.
- 7 Definitely. That's definitely something.

8 JF: So this is a nice place for you then?
 9 JB: It is.
 10 JF: Reflecting on it now () do you think your route is as much about coming past
 11 this () as avoiding people? Or is it both? If this is your regular route?
 12 JB: I hadn't thought about it but I think there's something in () in a sense of ()
 13 walking somewhere and you're walking past places that mean something to you or
 14 that hold a () special place for you. And I hadn't thought about it before but I
 15 think () it is interesting that we've come down this way.
 16 JF: And the way you described it is like containment you feel contained when you
 17 go in there.
 18 JB: Yeh.

John loves film and explains elsewhere how he escapes into a film's narrative, but the cinema is acting in a particular way to contain John affectively and physically. My affective notes reveal how I felt the space in terms of Bion's (1962) notion of containment. Bion refers to containment as the ability of the mother to hold on to and process the infants' unconscious anxiety and feelings. The term is also applied to describe holding on to one's feelings and responding affectively to them in terms of what they communicate (Clarke & Hoggett, 2009). Line 4 indicates that the metaphor has been activated and is being felt by John as a positive affect that is then articulated. Line 5 represents a metonymic displacement of this affect to the people who work at the cinema. In reference to my analytical frame previously outlined, it is possible that the significance of what is activated in line 5 would be overlooked. But the use of 'cocooned' in line 6 prompts scrutinisation of the textual context for active metaphors. Thus, cocooned reveals the saliency of line 5. The use of cocooned is a conventional metaphor that resonates with the notion of containment. Notice also in line 6 the boundary that is established whilst being cocooned in the cinema, in that 'everything else' is forgotten. This might be representative of a defensive splitting that brings to mind Klein's notion of withdrawal into the womb and avoidance of reality (Klein, 1930). This is a useful metaphor for thinking about how John's self is experiencing stasis and is unable to grow in light of his ME. However, it can also be thought of from an alternative perspective. The cinema as a metonymic displacement of the maternal womb can be used to think about the security, safety and unitary experience that the womb provides. But it is also a symbolic place where physical and emotional growth and maturation occurs (de Cortiñas, 2013). This indicates the polysemous nature of metaphor but also the requirement of some form of systematic analysis. By focussing on the saliency of the metaphor and its particular context it is likely that the womb metaphor is deployed in its first sense outlined above.

Conceptually, I noticed the displacement between John's ongoing affective state and a particular material environment. The cinema represents a psychosocial space where metaphoric processes are mapped onto a geographical space and suggests the entanglement between metaphoric and material space (Collinge, 2006); hence a space that incorporates John, real and imagined others, objects and a place connected by a route to other places.

To return to the notion of containment, the cinema brings to mind Modell's (2007) assertion that the body as container is a primary metaphor. In this sense the cinema embodies what John's body in light of ME can't manage: self containment. This represents the manner in which ME, the body, self and the material environment are mutually implicated. The degree to which John is conscious of this is debatable and illustrates why a psychosocial frame, where thinking about affective, social and psychological processes in a non-dualistic way, is useful. Note that in line 5 John refers to people in the present tense. This reveals the reactivation of a particular affective state at that time and introduces a temporal element and highlights how text can be scrutinised for shifts in tense that may connect to metaphoric processes.

Finally, during line 12, the video captures John shifting his body and facial expression. A moment of insight had occurred for him because my affective response had been articulated. I felt that his daily walking route was not only to do with avoiding crowds. I became part of that specific actor-network for John at that moment and the resultant effect was a moment of insight on his part. Moreover, it demonstrates the need for a psychosocial frame because it implies that whilst John rationalised his daily walking routine as avoiding crowds, there was also an unconscious response to the metaphorical space provided by the cinema and the route to it.

Whilst this brief analysis exemplifies my approach, the observations and extract are contextualised within an entire data set. The importance of which is that once actants are noticed, in this case of containment and a particular place, the task would be to establish whether they appear elsewhere and what else they associate with, so that initial ideas can be substantiated.

I considered specific methods from psychoanalytic practice to enhance how I noticed metaphorisation in interaction with the ME sufferer. Psychoanalytic methods that focus on the analysand's use of language include noticing how 'switch-words' are used

(Litowitz, 2013; see chapter 4), changes in vocal tone or subject (Cartwright, 2004), momentary inhibitions and facilitation of particular topics during discussion (Horowitz, 2011), interpretation of how metaphors cluster and their differences (Montana Katz, 2011) and slips and omissions (Schafer, 1981).¹⁹ Appendix 10 outlines instances of such events appearing in transcripts and the significance of these events in metaphoric and metonymic terms. I reiterate the potential overlap between metaphoric and metonymic processes and this extends to my interpretation of instances from the data. Rather than hard and fast rules, I employed my techniques in a flexible way that allowed for my reflexive relation to the data.

However, as noted by Cartwright (2004), the emphasis with psychoanalysis has been understanding and interpreting the unconscious processes that underpin the development of meaning. Whilst I have considered psychoanalytic and psychosocial literature to glean ideas concerning how to think about textual material and identify metaphorisation, I am not interpreting these in terms of unconscious processes *per se*. For this reason I have adopted and adapted Lisa Baraitser's (2008) psychoanalytic sensibility, echoed by Hollway (2009).

A psychoanalytic sensibility alludes to a:

“...way of working with human participants that instigates a constant re-working of the knowledge bases that we come with.” (Baraitser, 2008; p.426).

Given that psychosocial approaches are interested in how social and psychic processes infiltrate each other in ways that dissolve the inner/outer and social/psychological dichotomies, the psychoanalytic sensibility I seek to adopt entails not over emphasising the psychoanalytic aspect of psychosocial approaches. It is important to pay equal attention to the social processes that comprise the psychosocial and the manner in which the psychic and the social are already mutually implicated.

5.3.6 *Identifying ‘local’ and ‘global networks’*

In the previous section I outlined the framework that I developed and used to notice and think about metaphoric and metonymic relations between actants. In this section I

¹⁹ All of these techniques for noticing metaphor are language based and designed for use in clinical settings by trained psychoanalysts. The applicability and use of psychoanalytic concepts as research tools is a contested issue not only in terms of the ability of social researchers to apply such tools but also with regards to whether they are at all applicable outside of the clinical setting (Frosh & Baraitser, 2008; Hook, 2008; Parker, 2010).

describe how I moved from identifying a few actants that were apparently associated to being able to make broader associations across a given ME sufferers data.

Latour (1997; p.4) states that ANT “dissolves the micro- macro- distinction that has plagued social theory from its inception” and that there are not big and small networks, only differences in the intensity of associations. I found this useful when thinking about ME. It implies that anything can be enfranchised into a network and that following the actor ad infinitum would result in myriad, varied associations with other actants that were far removed from the initial actant both spatially, metaphorically and structurally. It also implies the fluidity of a network as different actants move in and out of it. But the research process has to end at some point. However, adopting this perspective on scale allowed me to shift between the particularity of actants and the actions they were involved in and the overall experience of ME on self.

For instance, I have described above with John a relation between actants that include a cinema, his daily routine of walking through town and an affective state. This can be described as a *local network*. I developed this term to describe a few actants and their initial associations as an early stage of the analytic process. A further local network for John involved paper. John hoards paper and this was beginning to physically fill his flat. Associated with paper was fatigue and anxiety. As I moved back and forth through the data and encountered different actants I was thus able to establish for each ME sufferer a number of local networks.

Once a number of local networks had been established, I scrutinised each one for specific actants and how they might be metaphorically or metonymically displaced into other local networks. For example, with John, local networks were built up around the cinema, paper, books, his father and emotion. By carefully looking at these in conjunction I was able to bring them together in a way where their associations could be established in a coherent sense. This became what I refer to as a *global network*. I employ this term as a description of a stage in the research process where I could begin to understand how ME was experienced by a particular sufferer and statements about ME in relation to specific material and non-material actants could be made in a broad sense.

To reiterate; I use the terms global and local network as organising principles as part of the analytic process. But in light of Latour’s assertion above, the terms also serve as a

tool to shift between the micro and macro aspects of ME. For instance between how a particular sufferer manages a symptom with a pill dispenser to how fatigue and anxiety might be defined as the contours between many disparate human and non-human actants and spaces that manifest as a specific self-understanding. In this way, consideration can be given to the broad social discourses that affect the subjective experience of the ME sufferer, such as delegitimisation. Thus, my use of the micro-macro distinction is more usefully thought of as ends of a continuum that enabled me to move between the social and intra-psychological aspects of ME in a non-dualistic manner.

Being able to think about ME sufferers in terms of global networks brought me towards the end of the analytical process. In the next section I discuss how I moved to understanding each particular experience of ME as an assemblage.

5.3.7 *ME as an ‘assemblage’*

The term assemblage reflects notions of complexity, chaos, indeterminacy, multiplicity and emergence. ME and its effect on self experience is comprised of concepts, experiences, viruses, bodies, material objects and places as a shifting mass; as disparate actors intrinsically associated in multi-scale, dynamic and fluid ways and effecting each other’s identity and delimiting how they act. ME as an assemblage is an apt way of imagining this complex arrangement and to frame the particularity of ME experience for a given sufferer.

Despite the usefulness of ANT in thinking about ME, it struck me that the term ‘actor-network’ felt like it described a two-dimensional arrangement.²⁰ This was despite the fact that ANT has had a large uptake in the discipline of geography, where it is utilised to rethink notions of space and scale.²¹ Assemblage on the other hand connotes a multi-dimensional arrangement. Focussing specifically on the indeterminacy of an assemblage, I read this as a statement about being unable to absolutely and ultimately characterise what the assemblage is comprised of because of its dynamic, non-causal and complex nature.

²⁰ See section 5.3.5 this chapter.

²¹ See for example (Collinge, 2006; Ruming, 2009; Allen, 2011; Saito, 2011; Aitken & Valentine, 2012).

In terms of each of the ME sufferers I worked with, I view their experience with ME as an assemblage because this metaphorises how each experience is comprised of different things that themselves have and define certain spatial and temporal arrangements and involve associations that are stable or unstable to varying degrees. Each experience of ME is particular to the sufferer and yet each experience may include similar actants that associate to manifest similar actions or define similar identities. So ME as assemblage is also a useful way of staying with the commonalities as well as the particularities of ME experience.

Thus, the end of the research process involved drawing an arbitrary line between the ongoing analyses for each ME sufferer. It involved subjective acknowledgement that I had worked on the global network for each sufferer enough to be as sure as possible that my descriptions of how actants associated and what this meant for the experience of the sufferer were justified by direct reference to the data. But it was also motivated by the need to complete the project as a whole.

Whilst this thesis is the written output of my work, I am left with an assemblage of each ME sufferer I worked with; a reflexive, affective and descriptive understanding of how ME has affected their self experience and how I was involved in arriving at that description. Each assemblage has to be understood as an incomplete and ongoing process and as an event that is still taking place for the sufferers concerned.

5.3.8 *Presentation of analyses*

Given my focus on the particularity of ME experience and the effect on self, I experienced a dilemma concerning how to present findings. I analysed all the data from all the ME sufferers I worked with but had to make choices about how to present these analyses, given the need for brevity. Three possibilities for disseminating the analyses presented themselves: three chapters addressing one research question each with extracts and instances from all ME sufferers, three chapters comprised of instances from all sufferers and various aspects of all research questions or three chapters, each representing one single ME sufferer.

The benefits of the first two were that a wider range of data could be included with instances from all sufferers. This also meant that all sufferers would be represented; which felt ethically correct, given how generous they had been in taking part. The benefit of the first approach would also maintain the integrity of each research

question. My final decision as to which method to adopt was influenced by personal history and the methodological stance I was attempting to develop.

During my studies in psychology, I have been drawn to in-depth psychoanalytic case studies of individuals because this resonated with Freud's use of individuals to build and exemplify his emerging ideas, as well as understanding and helping the individuals concerned (McLeod, 2003). I have also found that individual cases bring the real person into focus. In-depth case studies provide richness of detail and provide a way of addressing questions about how contemporary phenomena, such as ME, are experienced in real contexts (Scholz & Tietje; 2002; Yin, 2009). From the ANT perspective, the emphasis is on maintaining the description of the network from its own perspective and that such a description of an network, if adequate, should not require any further framing (Latour, 2005). This implies the need to retain the descriptive integrity of the whole case.

Finally, a central concern was to bring into focus the particularity of ME as a means of highlighting the subtle variability of each individual experience. Thus, I concluded that the best way to represent my methodology and the lived, particular experience of ME was to present one individual in each of three analytical chapters. However, choosing three separate cases meant that most of the data and sufferers I worked with do not appear in this thesis. This invokes in me a feeling of having betrayed those not represented and speaks of the emotional work needed on the part of the researcher to engage in reflexive, qualitative research (Clarke & Hoggett, 2009). Also, it might be suggested that selecting whole cases rests on a subjective bias on the part of the researcher (Achen & Snidel, 1989; Geddes, 1990). This is not an issue for the present research because the methodology makes explicit my reflexive involvement in the process from start to finish.

5.4 Chapter summary

In this chapter I have outlined how I selected and secured a group of ME sufferers to work with and how I translated my methodology into practical methods. I have also described in a stepwise fashion the analytical procedure I developed. My initial group of eight ME sufferers were aged twenty five to sixty five and represented a broad demographic. I used longitudinal, ethnographically informed methods over a six month period to enter into the everyday experience of these sufferers and their ME. Methods included partially structured interview and naturalistic discussion. These overlapped with participant observation of the everyday routines of the sufferers I worked with so that I could explore the relationship of ME to the experience of self in the material environment of their home and other familiar spaces and places. The research period consisted of five visits across six months which enabled snapshots of how self was experienced chronologically. My aim was to enter into the everyday routines of ME sufferers with the premise that I would approach how they experienced ME by becoming an actant in their actor networks. Audio-visual equipment was used to record all aspects of my interaction with sufferers. A central focus was to develop an explicitly reflexive method of participation that utilised my affective response to the sufferer and their world.

Data was comprised of verbatim transcripts of all discussions with participants, field notes and audio recordings of my affective responses, video recordings of interactions and writings provided by the participants themselves. The initial stage of analysis involved a thematic analytical approach so that I could begin to organise data and follow the actor. I reflexively acknowledged that I do not separate the data collection phase from analysis and this also reflects my ongoing reflexive response and evolving understanding. After the thematic analysis I moved to the core analysis, which involved tracing the displacements and associations between actants by identifying the metaphorical or metonymical equivalence between actants within and between domains. I outlined how I identified an actant and its associations in terms of displacement. To approach the issue of metaphor and metonymy I reviewed ways of systematising metaphor analysis and described how I identified metaphoric and metonymic relationships between actants. The notions of global and local networks were described as organising heuristics. Finally, I explained why I think about the end

result of the research, a description and personal understanding of each sufferer's experience of ME and its effect on self, as an assemblage.

In the next three chapters I present analyses of three ME sufferers as separate, whole cases. Besides the reasons described above, these cases have been chosen because they best exemplify a specific area of my research aims and as such I have selected material from each case that addresses a specific research question. It should be noted that I report on a limited number of actants and associations for each ME sufferer. Whilst these are adequate to exemplify my aims, many more actants and associations became known that provided further insights into the effect of ME on self. However, these have not been reported due to the limitations of this thesis.

Chapter 6

Bruce: Material actants, ANT and the mediation of self and ME

6.1 Chapter overview

The focus of this first analytical chapter is Bruce. The research question addressed is *how can material actants be used to explore the relationship between self and others for people with ME?* My focus comprises two main areas. The first area is concerned with how I adopted and adapted the ANT premise of *translation* as a frame to approach the data. To this end I utilise my notion of *local networks*; a tool for organising how I noticed, follow and begin to associate actants. I then discuss each aspect of translation in relation to Bruce. The second area explores further local networks built around specific material actants. Each of the networks described provide insight into different aspects of ME experience and its relation to self. These include how material actants become temporally displaced; providing a way of thinking about the associations between the people and emotional structures that Bruce encountered early in his life. I discuss how the ANT-informed perspective provides a non-causal way of understanding the relationship of ME to what might otherwise be deemed antecedent factors, such as anxiety. Finally, I explore how specific material actants associate as part of a complex process which results in what I term a *productive self*, enabling Bruce to address ME symptoms such as fatigue and offsetting the anxiety associated with appearing unproductive in the eyes of others and to himself. Throughout, I emphasise how specific material actants have become indispensable to Bruce's ongoing sense of self, his experience and management of ME and his relations to others. Material actants allow Bruce to concretise his self-understanding. They anchor Bruce's experience of ME, his relationships and how he narrates his self-understanding across his life span. The type of self described in this chapter is psychosocial because it is not reduced to either an essential, internal quality nor to external social reality. I maintain a tension between the self and ongoing relations and experiences in a material world and hence self is approached as mediated by material and social demands and restrictions. The chapter opens with a pen portrait of Bruce and descriptions of actants that appeared salient for him. Words and phrases appearing

in single quotations marks are direct quotes from Bruce. Actants have been highlighted in the first instance.

6.2 Bruce's background and central actants

Bruce is 57 and is head gardener for a country estate. He has two children with his wife, Jan; Rowena who is 17 and just completing her A' levels and Leo who is 18 and going to college. Jan has a son from a previous marriage; Alex. Alex is 29 years old and not in employment. At the time of this research Alex was in a secure psychiatric unit due to the bipolar-disorder he has suffered for 13 years. Alex's disorder has had a huge impact on Bruce and the family. Bruce has known his wife for 35 years. The family live in a medium sized semi-detached house and the garden is well looked after. Bruce completed a degree in chemistry at age 21 and then worked in the petrochemical industry for 3 years but gave this up to live in a tepee for 3 years in an alternative community in a Welsh valley. He eventually left this community to live back in 'mainstream society'. Bruce has a developed ideology based around being in tune with nature and describes gardening with passion. He stressed that the family eat mostly his own produce. Gardening for Bruce is an activity that connects to his ideological perspective. This perspective involves being in tune with the natural world. Bruce gardens intuitively and respects the history and nature of the ground. His belief is that gardening is always 'in process' and cannot be viewed in any final or absolute sense.

In 2005, Bruce completed a course in cranial-sacral therapy and began private practise. He had been 'working hard' and the therapy course had 'loosened emotional stuff but in a positive way.' After a weekend exhibiting at a local September craft fair he developed 'flu-like' symptoms that 'wiped [him] out'. He recovered but 'never got [his] strength back'. He cites this period as the onset of his ME.

A theme that runs in various ways through Bruce's narrative is the unemotional nature of his Dad and how this manifests throughout Bruce's relation to himself and others. Bruce also describes his Mum's unintellectual nature, which at times 'verged on impairment'. He attempts to distance himself from both these aspects in various ways, such as constructing himself as 'intellectual'. Bruce is also at odds with his self-perceived lower-working-class background in Birmingham and Birmingham itself, which symbolises a place he escaped from 'where the sun never shines'.

I first met Bruce at a self-help group. He struck me as a large man with an imposing presence, very articulate, passionate and educated.

The initial actants I describe for Bruce are **cooking** and **taste**. These pervade Bruce's entire data set and are important because, post-ME, cooking enables Bruce to engage in a productive and useful activity that is visible for himself and others. Bruce focused on taste in conjunction with cooking as his chosen activity for the third session. During this activity Bruce made various juices and fruit mixes with me and extolled the virtues of blending his own fresh produce.

Taste was his explicit focus for the fourth session, where it acted to enrol many other actants. He explains that his Mum's cooking was always 'bland' and that he was unable to taste things until a couple of years after his ME began. Bruce describes taste as 'multidimensional' but that the significance of these dimensions had not been apparent for most of his life. Beyond Bruce's life-long inability to taste, he also describes experiencing food sensitivities for ten years prior to ME. These have affected his ability to enjoy certain foods.

The actant **emotion** appears in different forms. Bruce explicitly relates his own emotional development to that of his parents, with his Dad occupying the dominant position in the family and setting the emotional tone in various ways. These include presenting a negative model of emotionality to Bruce, who acknowledges that his Dad was reprising his own emotional upbringing. Bruce describes his Mum as 'emotionally damaged' and unwilling or unable to talk to Bruce about his emotional needs. Overall, Bruce believes his childhood emotional development sets the tone for later relationships and self-understanding. He felt some 'need' to 'mimic' emotional relating and this may have impeded developing an 'authentic' sense of self. The important thing to note about emotion as an actant is that it represents a range of heterogeneous thoughts, feelings, behaviours, memories and material objects that have become displaced across time and place. In this sense, emotion is a way of describing the associations between these things and holding onto their connectedness and inseparability.

Anxiety is a further actant. Bruce describes suffering anxiety at many times through life and anxiety associates with many other actants. This was especially the case with the onset of ME. As a child 'most things made [him] anxious'. He roots this with his Mum. He tends to deal with 'anxiety-inducing things by avoidance'. Bruce conflates

anxiety with his own emotional response, which he describes as a 'bit buttoned down'. In terms of the relationship between ME and anxiety Bruce explains that sometimes 'you rationalise the experience of anxiety [associated with ME]. It's almost like the anxiety comes first.' This is important because it highlights that Bruce is not clear how ME and anxiety relate to each other. The implication is that not knowing what ME is has exacerbated anxiety for him as well as causing it. For instance, cognitive impairment caused anxiety because Bruce could not 'judge which queue to go in' in a supermarket. ME also resulted in anxiety due to an inability to tolerate noisy, busy, bright environments such as supermarkets. Bruce also explains that when ME occurred his emotional system was like 'a time bomb going off', with him experiencing extreme mood swings. He states that 'with ME, everything makes you anxious'. This includes the physical symptoms as well as the effect of ME on his ability to socialise and relate to others.

A further actant is **alienation**. Bruce references alienation from others whilst suffering hepatitis, around age 23, in that 'nobody wanted to come near [him]' and that he was 'a social pariah'. This was reprised with ME. Alienation is implicated when Bruce describes various societal groups as 'dispossessed' and 'seeking refuge' at the time when he lived in the Welsh tepee village. He states that 'there was a tide of damaged people flowing all around the country'; 'the inner city dispossessed'. Alienation relates to what Bruce understands as traditional classed structures. He identifies himself as working-class. In terms of his gardening he appears alienated not only from his employers but people in general who view gardening with 'a rational outcome'. For Bruce, gardening is a process of 'becoming'. This belies Bruce's highly developed ideological system.

However, alienation for Bruce is primarily from himself. Beyond emotional alienation associated with his father, Bruce was intellectually alienated from his mother. He describes her as simple, naïve and 'intellectually limited'. This primary alienation connects to how he felt about living in Birmingham as a child. His greatest wish was to 'leave that place as soon as possible', which he did aged eighteen. Bruce reprises the socially alienating effect of ME in that with its onset he was 'rapidly abandoned by friends'. Finally, Bruce conveys the sense of alienation concerning ME sufferers. He sets himself apart from online forum users by categorising them as 'chatty types', positioning himself as intellectual and focussed on finding useful scientific knowledge. He feels that specialists unhelpfully 'psychologise' ME. This latter point associates

with Bruce feeling that recovery from ME is down to him and not the medical profession.

Otherness is an actant. Bruce explicitly and implicitly describes various groups in opposition to one another. These include ‘purists’ contrasted with ‘middle-class’ in the tepee valley, upper class ‘super-rich’ and his family’s ‘working’ class, ‘damaged’ and undamaged, traditional members of society and non-traditional members, ‘ideologists’ and non-ideologists. Otherness appears explicitly and implicitly in his gardening work on a large, privately owned estate, with himself as a classed other, where he explicitly states that the ‘super rich are by and large unpleasant’. Bruce describes an ideology that emphasises harmony with the environment, respecting the ‘history’ of the land and approaching a garden not as a blank canvas but working as part of it. However, in terms of what his upper-class employers would make of this he states:

‘The people I work for at the moment if I tried to talk to them like that you know it’d be (touches his forelock) ‘get back in your box.’ ‘Yes master.’ For fuck’s sake! You know. [...] the people who actually have control who own these bright and cultural artefacts are ignorant, arrogant, selfish (*laughing*) and lacking in any sort of () social responsibility.’

This extract demonstrates Bruce’s sense of otherness in different ways. Beyond the apparent division along lines of class, Bruce implies that the [upper] class represented by his employers are unable to appreciate his ideological position and this establishes Bruce as an intellectual and enlightened other to the ignorant upper class. Bruce’s intellectual capacity is a defining feature of his self-identity and appears in various ways throughout the data.

Bruce implicitly establishes a general other who is unable to appreciate his ideology:

‘You know most people you say you’re a gardener they don’t really think about it in those terms. They think about it in very mundane terms. But although a lot of the work you do is mundane, part of the process is a lot more complicated and sophisticated.’

This extract suggests that Bruce is aware that gardening may be seen as a classed activity. He therefore deploys his ideology to offset this.

With reference to his first job in the petrochemical industry Bruce describes himself as:

‘... a bit of a mascot you know long hair and a lab coat. Fantastic! Wandering round. Me and me [*sic.*] boss in the research lab. People used to sort of like look askance! At the smells and whatever came out. But it was brilliant! We used to umm () break all the patents.’

The sense of otherness that this extract conveys is that Bruce is a rebel who resists social norms. A general sense of Bruce as a rebellious individual who resists the norms of society in various ways is apparent throughout the data.

As an ME sufferer, Bruce explains how non-sufferers ‘do not understand’ and do not appear to ‘share the same language’ as sufferers, who inevitably ‘can understand each other without barely a word’. These extracts indicate that Bruce has identified himself as an ME sufferer and hence this group is other to non-sufferers.

Whereas cooking, taste, alienation, emotion and anxiety might be described as non-material actants, I now outline material actants.

First are a **work bench** and two **cupboards** that Bruce has in his lounge.



These appear rough, ready, battered and purely functional and more suited to a workshop than a lounge. Bruce retrieved ‘only’ these items from his father’s house when his father died and describes them as ‘unemotional’ in design. Bruce had an affinity for these cupboards even as a youngster and explains that he got to see what

went in and out of them when he used to watch his father in his workshop. Bruce suggests that the reason he retained them was because they symbolised a ‘sense of control’ and how his Dad ‘extended his control’ and asserts that the garage was ‘his Dad’s domain’. This connotes that as a child Bruce was attempting to connect with his father by entering into his father’s world, where Bruce knew his Dad was in control and where he was allowed to enter but only to observe. The manner in which Bruce talks about them intimates the type of divided experiential world that Bruce inhabits.

Bruce also described a **food blender** and **juicer**.



These were demonstrated to me during our third meeting. Both are expensive models. Bruce takes delight in their design and explained their function to me in technical detail whilst disassembling and reassembling them. He uses the juicer every day to juice his own produce and add supplements to combat ME.

He described **bread and butter pudding** in the third session and made some for me to eat as part of the last session.



This actant associates with his Mum, who would make ‘tasteless’ bread and butter pudding when Bruce was young. Bread and butter pudding enables thinking about how an abstract category such as emotion can become displaced across time to reappear in the present.

During the third visit Bruce showed to me a **pill dispenser**.



This was a small device in its own Filofax-like cover, conveying functional efficiency and purpose. It was divided into seven compartments. Bruce explained how he would deliberate what vitamin supplements and pills to fill each compartment with on a weekly basis. The device served to augment his memory and was also important as a visual symbol of ME.

Now that the central actants arising with Bruce’s data have been outlined, the next section exemplifies how local actor networks were established.

6.3 Establishing local networks: the cupboards and the work bench

I begin this section by reiterating my adaption of key ANT ideas before focussing on how material actants are crucial to establishing relations between aspects of self-understanding and also represent a temporal and spatial displacement of other actants. Material actants are integral to thinking about aspects of Bruce’s broad experience.

Local network is a term I developed and used to describe how I noticed actants and followed them to the other actants they associated with, so that a small area of actor-network could be loosely described.²² Establishing a local network entailed adopting and adapting the ANT notion of *translation* to conceptualise how actants affect and effect each other, such that particular identities and actions resulted. The four moments

²² See chapter 5 (5.3.4).

of translation, *problematization*, *interessement*, *enrolment* and *mobilisation*, represent steps in the analytical process

Problematization

Problematization describes the manner in which an actor attempts to define a problem in its own terms, identifies other actors that the problem affects and how these actors can be redefined in the interests of a solution (Callon, 1986; Sarker, Sarker & Sidorova, 2006). I also use problematization as a way of keeping in mind that there are competing descriptions of how a network becomes established and to avoid foreclosing the analytical process. Problematization in my synthesis of ANT also describes how an event or question arises from the data and which appears to be pivotal concerning the ongoing experience with ME. This use is closely allied to Callon's use of problematization.

With Bruce, the actant 'emotion' presented as a problem that required following early on in my first visit; becoming salient when Bruce made explicit that his Dad 'was not a great fan of emotion.' Bruce identified that as a child he was obliged to suppress his emotional needs. Since that time he has identified that his emotional side has not 'been developed'. Consequently, Bruce has approached emotional problems, such as the emotional dynamic around his stepson, as a 'problem to be solved'. In other words, Bruce intellectualises emotion.

I decided to follow emotion as an actant due to its extensiveness throughout the data and because it associates with many aspects of Bruce's general history *and* ME experience. Moreover, emotion is clearly problematic for Bruce because of the manner in which it is entangled with his struggle to relate to people. In this sense, emotion is associated with Bruce's tendency to differentiate between various groups. However, I am not suggesting that emotion is causal to Bruce's ME but that it represents an ongoing problematic state that can be explored as an actant and which may lead to understanding an aspect of Bruce's ME experience.

In terms of problematization *per se*, emotion has defined and displaced itself through various material and non-material actants. For instance, the following extract exemplifies the dualistic nature of Bruce's understanding of emotion. Bruce is explaining that after his time in the tepee village he did not return to working in chemistry:

‘And I got there [*tepee village*] after the influx from the inner city dispossessed. So it had changed () big time. But you know it was still a very interesting place to be. Umm (3.0) yeehhh. So where did I go from there? () I got into gardening! And you know. Philosophically and physically it seemed to be perfect and I loved it. I always have I mean I really like () gardening.
 J: So when you'd been in that place [*tepee village*] and you came out you decided actively not to return to chemistry and industry and that way of life?
 B: Wasn't interested at all. Which is sort of a shame in some ways as there's an intellectual side to me that's not been developed () through that. But perhaps there was an emotional side to me that needed a different sort of environment () to be in. Yehh (3.0) and umm () so life after that was about () looking after children.’

This extract not only highlights that Bruce experiences a split between intellect and emotion but that he is connecting emotion to physical and extra-physical environments. Emotion as a problematic actor can be thought of as attempting to define itself through Bruce's relationship to specific spaces and places.

Thus, Bruce establishes emotion in a complex manner as part of a space that transcends geographical location. Intellect is connected to a different type of space. The intellectual space incorporates academic pathways and working in a scientific manner. In contrast, emotion associates with a space that is comprised of a physically different environment and perhaps where gardening acts in a metonymic way, such that gardening involves nurture, growth and care of the earth. As part of this space Bruce's emotional needs could also be nurtured, cared for and grow. The three second pause suggests Bruce was reflecting on his statement but given the shift in narrative to his children, it could also suggest that he was trying to recall chronologically what he did next. This is an example of problematisation in the sense that alternative explanations have to be held in mind until the point where one interpretation becomes more salient.

Interessement

Once emotion became salient, I began to think about how it might associate with other actants and whether it could be thought about in terms of *interessement*. Interessement, from the ANT perspective, describes how an actant begins to establish itself by co-opting other actants into association with it (González, 2013). Given the saliency of emotion, the task was to follow it to other actants to determine whether and how it organised other actants in its own interests. My opening questions in visit two involved following the actor [anxiety] from visit one. In the following extract, I have reflected

to Bruce that I had noticed a lot of anxiety talk during our first encounter and needed to follow it. Bruce replies:

B: (1.0) Um () gosh. Phwwaaaaw! Well, in terms of absolutes () I suppose () yeh, there's been different time in my life when I've hit anxiety quite badly. And certainly the beginning when this [ME] started it was like an emotional bomb going off. Somehow () the whole emotional system became unbalanced and you got really extreme swings. Not a () probably a bit buttoned-down emotionally or I certainly was when I was younger. Umm and umm () it's a tough one. I used ah () antidepressants to try and deal with that a bit. I used () beta blockers. Very effective! Um just when I had meetings with the boss because they were trying to sack me. So just at the time when I was least able to handle that sort of emotional (1.0) stuff [*due to ME onset*] it [*anxiety*] was hitting me the worst and it was a dreadful time. But since then I think if () almost if anything () emotionally I'm (1.0) I've not experienced emotions so much. Emotion-anxiety I'm not sure if they () fully equate. But () when you're really tired you don't experience emotion.'

In this extract, 'emotion' can be thought of as co-opting 'anxiety' and establishing itself as mediating Bruce's general experience, and later with ME, because even though he has been asked about anxiety, by the third sentence emotion has appeared. Prior to ME, emotion is established via the metaphor of an 'emotional system'. Bruce then connotes that with ME, this 'system' violently transforms. However, in the next sentence Bruce has deviated from the emotion/ME narrative to explain that he was emotionally 'buttoned down' when younger and this implies that Bruce is trying to reconcile his emotionality in the past with how he understands it today. Bruce then rationalises his use of beta blockers to try to 'deal' with his unbalanced emotional system and this reflects his general tendency to rationalise and intellectualise events. Bruce then suggests that since the onset of ME he has not experienced emotion 'so much', but this conflicts with many other instances where he describes the 'emotional roller-coaster' of ME. In the last two sentences, Bruce appears to be trying to repair, in a discursive sense, the way that emotion co-opted anxiety and became salient. The moves involved are: anxiety becomes salient over emotion because the anxiety associated with ME was 'hitting' him, emotion has not been experienced 'so much', emotion is offered up as potentially equating with anxiety and finally anxiety is prioritised over emotion because the fatigue induced by ME precludes the latter.

In terms of interessement, this extract reveals how emotion was not the conscious focus and yet it somehow revealed itself, requiring Bruce to work it into the narrative,

and has co-opted anxiety into a certain relationship with itself. Taking the previous two extracts together, emotion appears to be an object for Bruce that was not allowed to grow as a child, became connected to certain spaces where it can grow and has co-opted anxiety and intellect by asserting itself as an organising principle.

The following extract is from the fourth interview and again involves me following the actor; in this case the cupboards and bench.

J: You described him [Dad] before [*in a previous visit*] as kind of unemotional. And I think you talked about the work bench. As kind of functional, utilitarian and pragmatic. But without much umm () an emotional kind of flair I suppose I'm thinking because um when you look at this [*I turn and gesture to the cupboards*] it it does a job.

B: Yeh. He would of hated that in here. Cos for him () it was a functional bench in the garage and the reason the paint's on it is cos he used to () rub his brushes out on it.

J: Ahh right!

B: There's more coats of paint. Umm. And ahh (2.0) he had this thing about him. Emotionally () he did not like emotion. He didn't like showing it himself he didn't like other people showing it. Which could get quite extreme. Which I don't think is very healthy.

J: Healthy for you () to pick up...

B: Or him.

J: Or him [...] What made you think that I know you described these before but made you () retain these? Perhaps there were other things? Is there anything now on reflection that drew you too them?

B: I've had quite a bond with them from childhood. There's something about them. I think it's probably cos my father () used to lock everything up. Um () he was very fond of keys and er () you can see they all have locks. So it used to be like his treasure kingdom really. Boxes full of this that and the other () all locked away. Um () so...

J: What did that feel like as a boy?

B: Err (3.0) gosh...

J: Because the other thing I'm thinking is: you want to find what's in there. Because my Dad had similar. Things that were locked and you'd automatically want to unlock them. Do you have a sense of that?

B: Um (1.0) not so much because he would be in the garage when he was working and I would see stuff in and out. Um () but maybe it was this sense of control. The way that he extended his control. To (3.0) I suppose it was his domain. The garage. You know he was quite a clever man. He did a few () odds and ends I think people did more in those days they didn't have much else to do ha. Um () but (3.0) um () don't know.

J: Ok.'

What are the moves in this passage? Firstly, Bruce acknowledges the utility of the cupboards and that his Dad would not appreciate them in the front room. There then appears to be a break in the flow of narrative; Bruce is describing what his Dad used to do with the bench but hesitates and pauses before switching to focus on his Dad's emotional character, which implies that Bruce is experiencing a reactivated affective state associated with the cupboards and his Dad when Bruce was a boy. Bruce then reprises that his Dad's suppressed emotional nature was not beneficial to Bruce or his Dad. His next description of the cupboards can be understood in metaphorical terms. An interpretation is that Bruce related to the cupboards in a metaphorical manner. Whatever the cupboards held was translated into 'treasure'. The connotation is of something desirable, hidden or waiting to be found.

At this point in the discussion, Bruce and I are not sharing an intersubjective affective state because I am focussing on the significance of the locks and relating my own experience with my father's cupboards. A previous affective state from my childhood has been activated. However, Bruce refutes my idea, explaining that he got to see what went in and out and suggests the reason he retained them was that they symbolised his Dad's control. Stating that the garage was 'his Dad's domain' connotes that as a child Bruce was metaphorically and literally attempting to connect with his father by entering into his world where Bruce knew his Dad was in control, where he was allowed to enter but only to observe. If this interpretation is viable then the fact that the cupboards and bench were the only things retained by Bruce is significant. Bruce was not physically excluded from this world but was emotionally excluded.

The last sentence reveals that the affective substrate for Bruce is becoming unstable. There is a rupture where Dad is portrayed in a positive light ['he was quite a clever man'], then a more ambiguous light followed by Bruce moving towards a rationalisation and defensive humour. At the end, Bruce cannot tolerate the affective movement. He breaks off the narrative by negating his affective state, the cupboards and their reactivation of his Dad by moving into the kitchen, ostensibly for this reason:

'B: Yeh. I'm just gonna get the [*inaudible*]... [*Bruce gets up to get something from the kitchen*] Have a little bit of roll-mop. (10.0) Here. [*he returns and puts bottle of colourless clear liquid on table*']

Note the long delay before he returns. The kitchen was two steps behind him and the bottle had been on the worktop. This implies that he needed to break off from the affective space created around the cupboards and the bench.

Focussing on the cupboards and work bench sheds light on the relationship between Bruce, his father and emotion. The cupboards represent a metonymical and metaphorical translation of unemotionality in that both his father and these objects are/were unemotional. In this sense they maintain Bruce's relation with his Dad. The metonym can be pushed further by suggesting that they have become a displacement of his father and stand in for him. They represent Bruce attempting to make a connection to his father and perhaps embody Bruce's stark unemotionality.

It is also important that Bruce recognised the classed nature of these cupboards and bench. The cupboards' classed nature was made explicit by Bruce when two neighbours came to visit. These neighbours didn't like the cupboards, feeling they were not in keeping with Bruce's character. Bruce felt that the neighbours viewed them as 'middle-class' in that they represented the middle-class 'pre-occupation with salvaging antique objects'. Bruce suddenly recognised his alienation from these neighbours and he parted friendly company with them. The interesting thing to note is that these cupboards began life as pragmatic, working-class objects.

However, these objects in a front lounge represent what might be called 'shabby' or 'poor chic'. Shabby chic furniture is interesting because it represents a movement since the 1990s where the middle-class mimic what the working-class of previous generations actually had to do, which was repair and revamp old furniture. Whilst fully unpacking what shabby chic represents is beyond the remit of this thesis, Halnon (2002) notes that one such line of thought is that shabby chic provides a way of highlighting and poking fun at the traditional practices, symbols and artefacts of the the working-class. However, she also notes that the practice of shabby chic does nothing to actually eradicate the differences that class entails. I read this from a psychoanalytic perspective such that shabby chic provides a way of displacing and maintaining contact with the unconscious anxiety that having to acknowledge the [classed] other provokes. This is important in terms of Bruce's' cupboards.

Firstly, the implication that the neighbours recognised the cupboards as being at odds with Bruce is that they identify him as working-class. Bruce became alienated from the neighbours but one interpretation is that he actually became alienated from their

identification of him *as working-class* and this implies that he is attempting to detach his classed background. If Bruce was actually working-class, these cupboards as shabby-chic objects would be unfitting. Thus, two possibilities as to why the cupboards are in Bruce's lounge are that they embody his Dad or that they represent Bruce attempting to identify as middle-class and differentiate himself from his working-class background. In this case, Bruce has adopted them as shabby-chic items that allow him to perform middle-class and hence dissociate from his own working-class background. This interpretation is plausible, given that in the extract above Bruce had stated in reference to the bench that his Dad 'would of hated that in here', yet Bruce had given them centre space in his lounge/diner. Bruce may be differentiating himself from his Dad by defiantly placing the cupboards and bench in the wrong setting and in doing so reprising what the middle-class do but he may also be attempting to maintain contact with his Dad.

Overall, the cupboards and bench appear to be doing varied work. They are a displacement of Bruce's Dad and hence his unemotionality. But they also provide Bruce with the opportunity to resist his Dad. This resistance could represent a rejection of Bruce's classed origins but it is equally possible that they represent a rejection of his emotional origins. It is important that none of these options are rejected and instead the cupboards are imagined as a site of conflict where class and emotion have become conflated. Hence, when it comes to thinking about these cupboards in association with the actant of 'otherness, the otherness implied is not easily understood in terms of clear delineations between classes.

To return to the metaphor of treasure, the cupboards connote something waiting to be discovered. As a phantasised treasure object, the cupboards and bench provides the key to Bruce discovering and integrating his Dad as a whole object and hence himself *as well as* solving the conflated issue of his classed and emotional origins. This interpretation was evidenced when Bruce wrote to me unsolicited by e-mail [on three occasions]. On the second occasion, just after my second visit, he wrote:

'My Father died and I found parts of me that had been unavailable whilst he was alive.'

Whilst Bruce hasn't found the 'whole', those parts seem to be aspects of Bruce's emotionality. It appears that the cupboards and workbench are involved in

interessement and have co-opted other actants that include Bruce's emotion and his dead but metonymically present Dad.

To reiterate, Bruce has experienced anxiety throughout his life. He conflates anxiety with emotion and with ME. He is not sure whether anxiety leads to ME or vice versa. There is a need for Bruce to diminish the anxiety around emotion that pre and post-dates ME and to respond to the onset of ME and the way that it implies failure of his body and pre-ME self.

From Bruce's perspective, the interessement, the co-opting by emotion of other actants into networked relations acts to maintain some sense of self, bodily integrity and to minimise anxiety, which is displaced into the cupboards and bench. Material actants such as the cupboards and bench can be thought of as proxies of bodily and psychological capacities. The ANT-informed approach brings into view a new world of material actants that are equally important to the ME sufferer yet are subtle in their effect.

Enrolment

Interessement does not automatically lead to successful alliances and overall translation requires further reinforcement by enrolment (Callon, 1986). Actants have been co-opted at the interessement stage by a central actor and the defining of a problem, but the roles of these actants needs to be further defined by 'negotiations, trials of strength and tricks' (*ibid.* p,211) to ensure that they fulfil the needs of the central actor and the desired solution to the problem. Once I identified a central actant, such as emotion, and the manner in which it co-opted other actants into association with itself I subsequently moved through the data to discern the ways in which emotion defined other actants and also how emotion resisted the attempts of these other actants to impose an alternative identity upon themselves. I also used the term enrolment to think about the way that actants are associated in the emerging descriptions of local networks and whether early identification and linking of actants is validated by the later appearance of new actants and descriptions as I feed them back into subsequent visits.

For instance, an early actant I noted with Bruce was a large soft sofa with which Bruce had replaced his previous sofa, so that he could 'crash out' after coming home. I felt this might be a significant actant but in subsequent visits it did not reappear in discussion and emotion, in an actantial sense, did not appear to be co-opting it any way

I could discern. Thus, the sofa made visible an aspect of Bruce's ME experience but not to the same degree as the bench or cupboards and it did not threaten to assert itself in any problematic manner.

I reiterate that actors, artefacts and practices do not pre-exist networks but are outcomes or effects of these relations and emerging from processes of 'heterogeneous engineering' (Law, 1999). The material actants Bruce enrolls have potentialities that lend themselves to be enrolled in a certain way. In terms of the cupboards and workbench for example, when it came to thinking about enrolment, I questioned whether these objects held any potentialities that might threaten the manner in which emotion had co-opted them into a relationship. Thus, a different potentiality that the cupboards held was that they served a functional purpose because Bruce stores things in them and on them. The question was whether this potentiality threatened what I perceived as their association with emotion and whether their presence in the lounge was better understood in terms of their functionality. Approaching the cupboards and bench from the perspective of enrolment meant I had to further explore and interrogate their presence and in this sense enrolment becomes part of the heuristic of noticing and substantiating actants and their associations and identities. My conclusion concerning the cupboards and bench is that their interessement by emotion had been successful because of their metaphoric implication by Bruce in 'finding parts of himself'.

Mobilisation

The final moment of translation, is the point at which actants become spokespersons representing the network (Callon, 1991) and that the central actor "accumulate[s] enough allies in one place to modify the belief and behaviour of all others" (Latour, 1990; p.60).

Each actant in each local network has to be identified in terms of the action it is involved with and the identities it has potentiated. One way of managing this is by following the actor and checking descriptions with the sufferer. For instance, at the start of my second encounter I reflected to Bruce my affective response concerning his anxiety around ME and his alienation from others that emerged in the first interview. He corroborated my interpretations and affective response to the data as correct.

Having established a local network around Bruce's cupboards and bench and emotion, successful mobilisation meant advancing the analysis and not finding that the central actant of emotion reappeared in another setting with a contradictory identity. If this did

occur it meant that the cupboards and bench and other actants that emotion had co-opted were not exhaustively interrogated for potentialities or alternative associations. However, this is not to say that actants cannot act in contradictory ways (Latour, 2005). But if they do they have to be accounted for. By this stage, it was apparent to me that emotion was playing a central role in Bruce's experience of ME. It had displaced itself from his childhood and had reappeared in association with different material and non-material actants, such as the cupboards and bench, the space around gardening and the emotional disturbance caused by the onset of his ME.

This section illustrated how I adopted and adapted the ANT premise of translation as a frame to approach the data and research process. Translation has occurred in that a number of actants came into association and effected each other's identities in a dynamic relationship. The cupboards and bench can be thought of as spokespersons for the network in that they are materially stable and have been co-opted by emotion. Emotion, both as a presence and an absence and which is associated with Bruce's Dad, appeared as a problematic that required exploring and which has temporally displaced itself in different ways to appear in the present. However, networks are precarious and there is always the possibility that any of the actants I have described could act in an unpredictable manner and hence radically alter the associations that Bruce is part of and thus how he experiences himself and ME.

6.4 The pill dispenser and anxiety

Anxiety is a common feature of ME²³. In this section I illustrate how materiality and establishing local networks provide a means of exploring the relationship between cognition and anxiety.

During my third visit Bruce showed me a range of dietary supplement pills and a day-by-day pill dispenser. He explained that the pill dispenser relieved anxiety as it helped him organise his supplement regime. It acted as a functional adaptation to ME that associated as part of a local network around food and an ideology built around health equated with nature. Anxiety was identified from the first visit and reappeared at this time as I followed the actor. However, as noted in section 6.2, Bruce is ambiguous as

²³ For a discussion of the co-morbidity of anxiety with ME see (Lehman et al. 2002; Roy-Byrne, 2002; McCue et al. 2003), generalised anxiety disorder as a susceptibility factor (Wessely et al. 1996; Fischler, 1997), the relationship between cognition, ME and anxiety (DeLuca et al. 1995; Joyce et al. 1996; Short, McCabe and Tooley, 2002; Klasnja, 2014).

to what anxiety is, to the degree that he wonders whether it 'equates to emotion'. Bruce has explained that symptoms of ME include impaired memory and attention.

He states with reference to filling up the dispenser with various supplements:

'B: Each week I sit and think which ones will I use?'

J: Does this sort of thing make your life easier to organise do you think? Or can you dispense with it?

B: Oh God yes otherwise I'd have like a dozen different pots I'd be taking out each day. Plus each time I do it even though I do it each week I've got to sit and think: which ones will I use? Sometimes I'll just forget about something entirely.'

The dispenser validates and materially mediates an aspect of Bruce's ME experience. The ritual of filling up the dispenser acts as a sign of ME to himself and others. It signifies that because ME has affected his cognitive skills he needs something to mitigate such effects. It enables Bruce to control an aspect of his ME in terms of what pills go in the dispenser. As such, the dispenser is granting Bruce an agential means to address his ME. It also substantiates his cognitive failures such as memory impairment and reduced attentional capacity and is therefore a tangible and visible sign of ME. As an alternative description, it *may* also act as a material artefact that helps *maintain* Bruce's cognitive deficits associated with ME. This notion exemplifies that actants may act in different ways and that descriptions are contingent.

The pill dispenser potentiates an aspect of Bruce's ME identity and self-understanding and ameliorates some of the anxiety associated with it. However, the anxiety associated with Bruce's ME is entangled with pre-existent anxiety that he identifies from early in his life and this highlights the manner in which ME symptoms do not stand alone but seep into ongoing arrangements. Anxiety can be built into a local network around the pill dispenser and cognitive effects of ME, such that anxiety can be thought about not as causally preceding ME but instead as co-extensive with it in forms which have been temporally and materially displaced.

The pill dispenser provides a means of establishing how an aspect of anxiety is experienced and managed by Bruce but it is not a question of what anxiety is or does. Given the network premise of emergent identities and effects, anxiety is an instance where inputs and outcomes can be observed but the internal workings are hidden (Latour, 1987; Akrich & Latour, 1992). It is not the case that anxiety exists apart from

the network of things through which it emerges but instead can be understood as the associations between things rather than as a thing in itself; as a contour between actants. My ANT approach to anxiety is in terms of its performativity and as a process (Hartt, 2013) and a “consequence of the relations within which [it] is located” (Law, 1997). This provides an alternative to deploying anxiety as a thing in itself that exerts a causal effect, as from the biomedical perspective.

In terms of process, the ANT perspective is compatible with object relations conceptualisation of anxiety, where, rather than linked to a specific causation anxiety instead exists as a ubiquitous, unavoidable aspect of the human condition, arising initially from the infant’s overwhelming experience of helplessness.

The comparison between psychoanalytic ideas and ANT are such that in both instances, anxiety does not exist as separate from the network of objects, sensations and experiences through which it is registered. For Bruce, anxiety does not stand behind experiences in a causal sense despite him having made sense of his experiences of growing up and ME by labelling some of these relations as anxiety. The difficulty is that if anxiety is an inherent part of being human and experienced as an interior and fundamental aspect of self then its representation will always fall short of how it is experienced. Thus, whilst Bruce’s pill-dispenser provides a symbolic means of understanding an aspect of his anxiety, there will remain an interiority of experience that cannot be symbolised. I have attempted to retain this sense of interiority by not attributing a cause to Bruce’s anxiety, by allowing anxiety to describe itself in the terms that Bruce uses and providing a picture of how extensive anxiety had been for Bruce across time and different experiences. In other words I have attempted to provide a sense of anxiety as an ongoing feature that weaves in and out of Bruce’s life.

6.5 The food blender and juicer

In my second visit, with a focus on material actants, Bruce talked about and demonstrated his food blender and juicer. He explained them as highly significant in allowing him to ‘experiment with flavours’ and prepare healthy food. The aim of his healthy food regime is to combat the symptoms of ME. As with the pill dispenser, the blender and juicer also allow Bruce to carry out a useful function that is visible for others as well as himself. He blends and supplements various food stuffs on a daily basis:

‘I got the blender because I couldn’t () I’d didn’t have the wrist strength to make pastry. And um I got that [*liquidiser*] for smoothy type stuff. And I got this one for doing () fruit, vegetables and um () wheatgrass. To try and ah () well () nutrition really to give me as much in the way of minerals and vitamins and stuff that I could.’

Besides acting as a displacement of Bruce’s wrist weakness, the blender facilitated a discussion about Bruce’s food intolerances and how the content of vitamin pills is ‘ludicrously low’.

The potentialities of the blender and juicer became relevant at the moment of *interessement*; at the point where Bruce was suffering ME symptoms. Given his knowledge of health, gardening and his nature-orientated ideology, the blender and juicer co-opted themselves into a local network and defined their identities as indispensable to Bruce’s emerging health regime. What I am emphasising here is that the identity of these actants only emerged in light of the way that they associated with other actants in an emerging network. Thus, the identity of the blender and juicer is not a fixed attribute that pre-exists *interessement*. With a different individual, a blender may not become a sign of the self and of ME in the same manner. Instead it may signify failure or resentment. This goes for any actant. Its identity is an aspect of the whole network and established through its associations with other actants.

Bruce’s understanding of nutrition appears central to his ideology and how to treat ME. The value of the blender and juicer is that they offset the anxiety associated with an aspect of Bruce’s ME, namely that ME may be related to a nutritional deficit. However, there are further associations which are equally salient yet perhaps less apparent. There are two central threads of association here. Firstly, Bruce reprises the standard discourse that the medical profession do not care or at best are unhelpful. He states that:

‘J: So your improvement () is down to your hand?

B: I think I’ve done it in spite of the medical profession. They’ve done nothing to help me. And got in the way. Either directly or indirectly. I had to send to the States to get () half the supplements I use ha.’

This extract illustrates an association with the actant of ‘alienation’. But it points to alienation not only from the medical profession in an abstract sense but also in a geographical and spatial sense, given that he has looked to the USA for what he needs, which brings to mind my discussion of emotion and ‘space’ in section 6.3. This is

substantiated elsewhere in Bruce stating that ME sufferers get a 'better deal' in the USA and that USA online help forums are more useful. Alienation also associates with Bruce's intellect and chemistry background in a way that points to alienation from others as well. In the following extract Bruce is explaining that after the onset of ME he began to look to his diet as a means of addressing symptoms:

'So I started moving more towards meat. But it tended not to be () heavy duty meat. It tended not to be () red meat or anything like that. Quite a light diet. But um () sooo and then I () ah yes! Salt. I used to use low salt high potassium low sodium. Um () but one of my problems seemed to be low blood pressure. I got a blood pressure monitor and checked that through the day. And when I felt rough I very often had low () blood pressure. So I started drinking more liquids and eating more salt. On my food. Umm and going back to a straight salt. And that helped. So that was quite good. So then I started looking at (1.0) um I think it was DHEA [*supplement*] and trying that. And that was extraordinary. I mean within a week I was feeling the difference. So I gradually upped the levels of that. And there's a thing called SAMI [*supplement*]. Which is very good and umm () a supplement of B-12. Because quite a lot of doctors particularly in the States give injections of B-12. But they never would here like they never do anything here! So umm I found this sublingual [?] because it doesn't go through the gut very well. It would take a lot to try to get it through the gut. Particularly this umm methylcobalamine which is umm (1.0) often they give you cyanocobalamine which umm and it seems to be the methylation which is really important in quite a lot of these issues especially around umm mitochondrial function.'

Bruce is calling on his technical knowledge and intellect to substantiate the supplements he uses and is rationalising his experience of ME into a problem to be solved. He approaches symptoms in a quasi-medical manner. Overall, the blender and juicer becomes sites where Bruce can approach ME as a 'scientist' and this might suggest that these actants enable him to objectify, and distance himself from, ME. In this manner, the anxiety associated with his symptoms is managed.

However, the blender and juicer are also a sign of Bruce's alienation, intellect and ideology. They have become indispensable to Bruce. In ANT terms they are an obligatory passage point (Callon, 1986) crucial to Bruce's self-understanding and its enactment. The implication is that the aspects of Bruce's self experience with ME can only be resolved by 'passaging' through the blender (González, 2013). The ongoing movement between actants in and out of a network encourages thinking about the ways in which Bruce's self experience is fluid and phenomenologically different at different times and entangled with material artefacts.

6.6 Cooking and a productive self

In chapter three I discussed qualitative work that has explored trajectories of the self in light of ME. In this section I explore a local network that constellated around ‘cooking’ and how this associated with actants such as Bruce’s Mum and which gives light to the manner in which Bruce sought to establish a productive self in light of the effects of ME. The term *productive self*, which did not occur in my literature reviews of either ME or self captures Bruce’s attempts at restoring or creating a self-aspect that assuages the negative impact of ME in a way that is demonstrable. The term reflects the general notion of attempts to recreate or restore a more positive self that ME literature *does* reflect.²⁴ However, what I seek to emphasise in terms of ANT is that Bruce’s productive self arises as an effect from a network of actants that include social discourse about ME, doubt, real others, fatigue and specific material actants.

In our third session, Bruce stated:

‘Cooking has been the road back from the abyss.’

‘Cooking’ appeared to me to be an actant that needed following. In the second visit I had asked Bruce about the significance of food. In the past, cognitive impairment has been so bad that he:

‘...could not hold and follow a recipe in his head.’

Concerning his partner, Bruce states:

‘And then of course with ME () I couldn’t even stand up. I couldn’t stand up long enough to cook anything. To even walk. Um (1.0) and so Jan (1.0) did Jan do the cooking I’m trying to think. Yeh. She’s a teacher so she works quite hard and comes back quite late. And um () I think the pressure was on me to cook because it seemed like I wasn’t doing a lot really apart from lying around all the time. So I’d take a chair in the kitchen () and stand up enough to sort of get something on then I’d sit on the chair. And just do it like that. And quite often I’d come home from work, I’d fall asleep, for two three hours () I’d wake up come down cook tea () and then go to bed! Because that was it. That was my life for () at least 18 months. If I’d been living by myself I probably wouldn’t have eaten because I was so tired and I couldn’t be bothered. I really () just () I didn’t do anything I didn’t have to do. Down to the most minor thing I wouldn’t get up off the chair I wouldn’t pick up a cup. I wouldn’t do anything that I didn’t have to do. I was so tired you couldn’t

²⁴ See Charmaz (1987); Clarke & James, (2003); Whitehead, (2006).

believe it. So probably (1.0) um I don't think she really believed me for (1.0) at least two years. Umm which is a bit difficult. I sort of understand it and it's just who she is. Um but () it's a bit tough. Um so yes I felt a degree of um pressure from her to do (1.0) at least the cooking.'

Bruce's partner can be construed as an actant that appears in this network and is implicated in his sense of self before and after 'cooking'. He explains that cooking became 'a life line' to him; something he could be productive through. The chair is significant as an actant because it is also a material instantiation of Bruce's ME that signifies his compromised abilities. It acts as a sign of the self and for his wife. It substantiates fatigue because without the chair his fatigue precludes activity.

Bruce had also explained how his Mum's cooking was 'not experimental' and that she was 'limited' intellectually and by the 'spirit of the age':

'Um () so () in some ways it's like I look back and I think about her cooking and how that worked and I think well why did it work? Because () it could have been a lot better she wasn't experimental. She did things probably the way her mum had taught her to. Umm () and umm (3.0) yehhh. (3.0) So it's about limits. About () how we are all limited. And exploring your limits.'

But Bruce had also described his mother in the first visit as:

'...naive, emotionally damaged.'

And his emotionally neglected general development was:

'...to do with the emotional structure () in the family.'

As a child, he:

'...wasn't allowed to question or ask...'

And:

'You become accustomed to accepting one thing, even if your senses tell you another.'

There thus exists an association between cooking, his Mum and emotion.

I also asked Bruce if he helped cook as a child:

'I wasn't involved in it all. My Mum did the cooking () very traditional. My dad went to work. My dad expected his tea on the table um () and my mum () cooked () very simple food. We were very () you know we were quite poor

so it was very simple. She bottled things that we went out and collected. [...] She used a pressure cooker a lot. It meant that () every vegetable pretty much tasted like every other vegetable. Um ha ha. Her cooking wasn't exactly cordon bleu.'

And that:

'B: [...] My father was very much ah () unadventurous. He wouldn't have any spices () pepper, onion. Anything like that in food. In food. So I guess () maybe I grew up on very bland food. I never really thought about it. [...] I think physiologically I was ok. But thinking about it cos it's an odd thing () I suspect it's much more to do with childhood structures () in perception. Um () I suspect () a bit like seeing: you see what you expect to see most of the time. And if you're fairly strongly conditioned to seeing a particular thing () then that is what you'll see. And I suspect tastes may be the same.

J: So you're saying you grew up not with an active awareness but with an absence of taste? That you never noticed? Perhaps?

B: Possibly. But I think it must be more than just the physical () um () you know () taste of food. I think it's got to be more of a () probably emotional structure. Within the family. That around food there would have been () some sort of emotional charge between my mother and () I don't know I mean. She had to make do with very little. So () getting the most out of food was () I mean their relationship was very restricted and quite () traditional.'

Bruce goes on to think about his emotional capacity in terms of 'conditioning', reprising discussion in the previous session about 'being conditioned not to ask or see and to accept the 'double-think of feeling one thing and being told another'. The 'charge' around food is twofold: the emotional restriction from his Dad physically restricts Bruce's ability to taste food. In other words Bruce's emotional capacity is metonymically displaced into food as an absence.

Secondly, the impoverishment of the period may have introduced an emotional dynamic between his Mum and Dad that Bruce engaged with unconsciously and associates with the alienation that Bruce feels. This and their material surroundings began to establish Bruce's sense of class, which became conflated with burgeoning emotional alienation from self and parents. It is not that a working-class origin caused Bruce's alienation from self and other. Instead, Bruce's alienation, sense of self, otherness and class are potentiated in many non-material and material actants and is realised as an identity at the network level which can be explored by building a local network around cooking and taste.

So what is happening around the actant ‘cooking’? Firstly, cooking provides a space where Bruce can explore his limits and demonstrate a productive self. Because of his wife’s doubt about Bruce’s ME he had to find a way of demonstrating a productive self as well as being able to experience a productive self.

Secondly, the space around cooking connects Bruce to his emotionality and his mother. Metaphorically, cooking can be thought of as reflecting a productive self infused with his mother, but it also represents a space where he can define himself as different from his mother whilst retaining emotional contact with her. Cooking may be the road back from the abyss for Bruce but this involves more than demonstrating and experiencing the capacity to be productive. From the ANT perspective, it demonstrates how this arises as part of a complex process involving different kinds of actant that are co-extensive. This is because the conditions of emergence of his cooking-orientated productive self antedate the appearance of ME.

6.7 ME and the return of taste

A second chain of association is the way in which ‘taste’ is implicated with ME in as much that before ME, Bruce ‘could not taste’ but with ME, taste returned in ‘Technicolor’:

‘J: Going back to the food thing then. You started to talk about food and that your taste (1.0) or your tastes () had changed.

B: Yeh. I was always used to having homeopathy so I thought: ok I’ll use homeopathy because the doctor’s no good. And umm (3.0) phwaaw I tried a couple of things. You know. Didn’t lead to very much. And um () I tried this other one and um (3.0) blow me! I just tasted () like I’d never tasted. It’s like a black and white world turned Technicolor. It was unbelievable and I was [laughs] sitting there and I don’t know what it was. It was probably a carrot or something and it didn’t have to be anything much it could be anything...’

Bruce describes the rate of reappearance was ‘over a day’.²⁵ Prior to ME Bruce suffered ten years of food sensitivity to many food-stuffs. With the reappearance of taste this disappeared and he states:

‘And with this sense of taste came () I started blending tastes. So I started understanding food in a way that I’d never understood it before.’

Subsequent to the third visit, Bruce sent me some writing via email:

²⁵ A positive experience which complements work that suggests ME can effect positive and negative changes; see for instance Clarke & James, (2003); Dickson, Knussen and Flowers, (2008).

‘I wrote “initiating factors” shortly after your last visit, I guess it stirred something up.... []... I would like to focus the last session around ‘Taste’ as it has been my route back from the abyss. I’m sure it will be interesting and fun....’

This writing implies an affective movement in Bruce and that an insight into his ME has arisen through the research process. Bruce focused on taste, in conjunction with cooking, as his chosen activity for the fourth session. Taste associates with his Mum, cooking, his Dad and emotional structures. Bruce’s stilted emotional nature is instantiated through the material actants of taste and cooking and runs through Bruce’s practices and behaviour today and his experiences as a youngster.

In the following extract, Bruce has been explaining how he wanted to cook things for my last visit but that he wasn’t sure how it was going to turn out:

‘Cos although I’d thought about the dishes and how I was going to lay them out on the table () I couldn’t actually think () how it would work. It was almost like setting up a space () and then () whatever happened happened. I didn’t know what it was going to be.’

What is the significance of taste for Bruce and why did he build the last session around it? To convey the scene, the following screen capture shows the food Bruce had prepared for me:



The dining table was arranged with many food stuffs he had prepared for us to eat, most of which, and most significantly the bread and butter pudding, were sweet foods from his childhood that his Mum used to prepare. He explained that this session was a 'learning experience for him'. He had written three pages of notes and spent a week planning this activity. The degree of planning was 'exhausting' for him, although the notes helped him keep track and organise his thoughts and this he connects to the detrimental effects of ME on cognition; another material instantiation that was visible for Bruce and myself. ME was present in a way that may not immediately be apparent but became apparent when the focus was on the material world.

Bruce started the session by giving me a cup of expensive macha tea. He invited me to the table to 'play with taste!' I jokingly asked if I had to eat everything:

'B: You don't have to eat it all. The idea is it's tastes. That's what () and it's a whole variety of tastes. In terms of () well I thought in terms of nurturing tastes. So there's some things which () my mum used to make. So bread and butter pudding, and (1.0) rice pudding. This is umm () bananas made with mashed with condensed milk. Which was...'

Bread and butter pudding is an actant that effects a temporal displacement of emotion from Bruce's childhood. Superficially it equates with his mother and nurturance. However, Bruce explained that his mum's bread and butter pudding 'was tasteless but his won't be'. Using ANT to trace associations provides a means of thinking about how material actants such as the pudding translate directly from the past and into the present. More importantly, given Bruce's comment previously in this paragraph and that his Mum's cooking was 'tasteless' and 'non-experimental', bread and butter pudding became an actant through which Bruce can differentiate himself from his Mum in that his pudding was experimental, tastes better and is not impoverished.

It is therefore useful to think about the pudding from a psychoanalytic perspective. Bruce's suggestion that his pudding will be tastier than his Mum's suggests that he is splitting off that part of his Mum that is bad and has become associated and symbolised in her inability to cook, tasteless food, emotional damage and inability to nurture Bruce. The latter observation is doubly important in that Bruce was not nourished literally or emotionally. In contrast, Bruce also states that his Mum did her best with what she had. In this sense, the pudding is a material displacement of Bruce's childhood affective state and its evolution with his Mum and the environment.

I also note that in preparing the food table for me, Bruce was carrying out a nurturing role. He fed and nourished me. In this sense, the spread of food Bruce prepared felt as though he had tried to identify with his Mum by doing what she could not do. The pudding then becomes a site with which Bruce maintains contact with the good and bad parts of his Mum and through which he can carry out reparative work, in an unconscious sense, that mitigates the anxiety associated with feeling that his Mum had bad attributes.

Therefore the significant aspect is the reappearance, if not the ongoing presence, of the real external object [BB pudding]. Material objects thus provide a means of bridging past states with present ones and hence provide a way of noticing and exploring issues of temporality. At the time, my affective notes reflected that the appearance of the pudding on that table struck me as overwhelmingly important. Through his Mum's pudding and his Dad's cupboards, Bruce's parents and his affective relations with them are still present for him in a displaced material sense.

It appears that taste as an actant can be described in association with cooking, his Mum, bread and butter pudding but also with the research process itself, which has 'stirred something up'. Given the association between Bruce's fatigue, cooking and taste, ME can be understood as inseparable from Bruce's emotional history and ongoing material environment. Moreover, because of the manner in which actants have been temporally displaced for Bruce his productive self reflects a response to ME as well as the ongoing arrangement of actants in effect from his early life. In this sense ME is entangled with Bruce's whole life experience.

Bread and butter pudding anchors what might be called self and implies how self experience in the present is comprised of material actants as well as past relationships. 'Taste' and 'cooking' are non-material actants that mediate Bruce's relationship to his past and simultaneously his changing experience with ME. However, the relationships between all these actants and others that potentially did not become known during my research are difficult to reconcile from a causal perspective.

Considering 'emotion' as an actant associated with 'taste' provides a way of thinking about antecedent factors in relation to ME. From this perspective, ME does not stand apart from materially oriented practices nor from self experience. Instead, they are entangled in a non-causal manner. Material artefacts can be understood as part of the

self, without which self-understanding and experience could only exist in an abstract sense.

Objects signify and objectify the self to our self (Rochberg-Halton, 1984). This notion can be used to think about self in different ways as it indicates how objects carry potentially opposed values, such as Bruce's bench or his pudding, or enable the construction of dual meaning and acquire a specific history depending on the sociocultural relations they become involved in (Epp & Price, 2010). For instance, bread and butter pudding has a long history but is usually associated with the need to avoid wasting food, particularly stale bread. In this sense, the pudding is associated with impoverishment, those who cannot afford waste and hence is classed; especially true during the frugality of the post-war era. Thus, bread and butter pudding potentiates the negative aspects of Bruce's early relationship with emotion *and* his perception of working-class and alienation. It also potentiates the positive aspect of regained taste and productivity of self via cooking.

Conradson (2005) views self not as bounded but as emergent and relational within and through its encounters with others and events. This view comes to mind in as much that Bruce does not talk about ME in isolation but segues into fundamental aspect of other self experiences that involve displacement in many directions. In this sense, self is distributed across actants and the practises they are involved in. This is somewhat different to previous literature that investigates the effect of ME *on* a 'self' which appears to be less problematic because of the implication that self is innate, bounded and divorced from materiality. If self in ME is understood as relational, antecedent factors such as emotion have to be reconsidered in non-causal terms because they do not sit behind and cause ME but are instead co-extensive with it. Moreover, Bruce depends on the materiality of the blender and pill dispenser to maintain specific aspects of his self understanding and experience of ME. From the ANT perspective one can hypothesise that if the blender fails or the dispenser is lost, a momentary disruption would result and Bruce would experience self in a disequibrated way until the items could be repaired or replaced and the networks built around the blender or dispenser re-stabilised. Alternatively, the loss of these actants might result in a new aspect of self, new ways of coping or the enrolment of other material actants and hence a different experience of ME.

6.8 Chapter summary and conclusion

The research question addressed by this chapter was *how can material actants be used to explore the relationship between self and others for people with ME?* The aim was to describe the manner in which Bruce and his history associated with material actants when talking about post-ME changes to self. The actants allow Bruce to concretise his self-understanding and provide an anchor with which to experience and talk about changes to self and to maintain contact with and renegotiate aspects of self-understanding across his lifespan.

For instance, cooking appears to be important to Bruce post-ME. But when considering this productive activity in association with other actants it is clear that cooking is as much the end result of a series of long-standing displacements as it is new. One explanation for the types of self deployed in ME research is that they reflect specific methodologies and epistemologies as much as an actual state of affairs. Asking a sufferer to describe how ME has affected their life may result in a restricted narrative that focuses on ME symptoms or diagnosis but not what other aspects of ongoing experience may associate with these across the lifespan. This limits the ability to contextualise the particular experience of ME.

I have tried to bring to attention a way of thinking about self and ME that challenges the notion of the ‘rational and autonomous human’ (Frosh & Baraitser, 2008). For instance, from a rational perspective, Bruce keeping his Dad’s cupboards and work-bench makes sense because they act as a reminder of his Dad and they have pragmatic value. However, by exploring these as actants that embody Bruce’s Dad and unemotion, they take on a less transparent character. The cupboards and bench are saturated with various affects that make sense to Bruce in ways that have no objective relationship to the cupboards and bench themselves. My perspective contests rational notions of self, given that I described how interactions in the present contain symbolised interactions from the past, such that the past has been temporally displaced.

A psychosocial perspective challenges the notion of Bruce as autonomous and in charge of a rational self that has engaged with ME as an object wholly in the external world. ME has become entangled with long-standing actants in Bruce’s life such as anxiety and emotion and has resulted in further anxiety and emotional issues. It is difficult to establish the boundaries between Bruce’s history and ME as actants blur

into each other. From the relational ontology of the ANT perspective, actants such as the cupboards, blender and dispenser have their own material reality and hold various potentialities. They have equal standing with Bruce in the networks where they appear. Pushing my perspective to the limit, they have imposed themselves on Bruce and effected aspects of his self as much as he has imposed himself on them.

For instance, the cupboards when Bruce was a child acted as a phantasised bridge between Bruce and his Dad. Today, they embody the ongoing relationship between Bruce, his Dad, his emotional nature and so on in a manner where what affectively belongs to Bruce and what has been shaped by the cupboards is unclear. Similarly, the bread and butter pudding is part of the ongoing, dynamic relations between Bruce, his Mum and social class and in this sense the past really is present for Bruce today. From a psychosocial viewpoint, the associations between Bruce, the cupboards, bread and butter pudding and emotion transcend a simple inner/outer dichotomy and bring into question how past and present relate to each other.

Illnesses such as ME render one's body and one's sense of self as other to the norm of the healthy self (Driver, 2005). The way ME transforms identity can be seen as positioning the ME self as lying outside and other to the normal pre-ME self (Asbring, 2001). ME is therefore fundamentally alienating. It is also well documented that ME sufferers are socially marginalised by scepticism about the veracity of the condition (Charmaz, 1997) and this was particularly pertinent for Bruce. Also, disabling illnesses and sick bodies denote for the well and healthy the tenuous nature of human physicality. This can result in anxiety which is defended against by consigning it to the ill-as-other, resulting in further social alienation (de Wolfe, 2002) and perhaps connoting the psychic aspect of the psychosocial.

Otherness implies power because group relations often involve power differentials, with perhaps the more powerful group having greater resources to define the identity of the less powerful group and to imply the latter as inferior and as other (Okolie, 2003). This social aspect of otherness is also relevant to an analysis of Bruce's experience with ME. His conscious awareness of the power differentials that working for the landed gentry entail is already infiltrated by the anxiety outlined above. In this sense, Bruce's experience of otherness and its relation to self with regards to his ME can be usefully explored under a psychosocial light because it provides a perspective on the complex interplay of the psychic and social processes that otherness entails.

The type of self that I have alluded to in this chapter is psychosocial because I have not reduced it to either an essential, internal quality nor to external social reality. I have attempted to maintain a tension between the self and ongoing relations and experiences in a material world. In other words, I have approached self as embodied in the world and mediated by material and social demands and restrictions (Millward & Kelly, 2003).

Focussing on anxiety specifically, I described the ways in which anxiety can be thought of as “a consequence of the relations within which [it] is located”. This statement is necessarily tautologous because I want to think about anxiety as psychically and physiologically experienced but also as materially and socially mediated and produced at the same time as being experienced individually, by Bruce, in particular ways. Anxiety from this perspective resists objectification and this is different from biomedical approaches.

In conclusion, an ANT oriented approach to ME enables a reconsideration of self in terms of its instantiation with materially oriented practices. By thinking about the material displacement of abstracted categories, such as emotion, the self and its relation to ME becomes less abstract and more particular. There is however not necessarily a one to one correlation between an actant and what is displaced with it; bread and butter pudding does not immediately lend itself to an understanding of Bruce’s emotion, childhood relations with real others or the effects of ME. ME from this view is continually constituted and reconstituted in the associations between disparate actants as they co-exist and co-interfere in dynamic ways (Aberton, 2012).

Chapter 7

Whimsy: Using metaphor and metonymy to trace associations between actants

7.1 Chapter overview

Chapter 6 described how ANT was used to trace the temporal and physical displacements of material actants. The present chapter takes up my adaptation of the notion of displacement with the emphasis on how ideas about metaphor and metonymy extend the ANT framework. The research question addressed by this chapter is *how can metaphor and metonymy be used to explore relations between actants?* Whimsy has been selected because the actants that became known through her data highlight how the physical environment, events and specific features of ME become entangled. Metaphor and metonymy enables a shift from certainty about causes of action to the non-causal uncertainty of describing who and what is acting and how (Latour, 2007). Metaphoric and metonymic relations involve describing, explaining or experiencing one thing in terms of another. In this sense, a key aspect of the way that metaphor and metonymy work is that they unite different actants in a non-causal manner and in doing so act as a bridge between past and present states. Using metaphor and metonymy to imaginatively explore the associations between actants provides a way of retaining the unique and subjective nature of ME as well as the confusing relation between body and self and the contradictory aspects of what people say, do and feel.

I begin the chapter by presenting a pen portrait of Whimsy. I present descriptions of how Whimsy experiences ME in terms of her specific beliefs about energy, how she understands events that have happened to her in life and how these beliefs and ideas can be explored in terms of their metaphoric and metonymic relationships. One of the threads running through my analysis is the way in which ‘death’ has become associated with Whimsy’s neck via a series of metonymic equivalents. Whimsy’s neck is for her the focal point and embodiment of ME. I focus on the identity that Whimsy’s neck conveys on her in terms of a site of vulnerability that affects ‘romantic’ relations. My discussion of this association highlights the relation between ME and how it is associated with real social relationships and the manner in which real others become imagined. A further thread, also associated with Whimsy’s neck, concerns how she understands energy. Exploring the ways in which ME sufferers experience and

understand energy is highly salient, given that low energy is a common feature of sufferer's experiences and psychiatric and biomedical concerns with characterising and managing ME (Carruthers et al. 2011; Heins et al. 2013). I describe how Whimsy deploys a particular understanding of energy that involves mechanical metaphors of the body and bodily processes. For Whimsy, ME equates in part to an energy flow that is blocked by her neck.

Connected to the issue of energy is the the notion of *debilitating space*. This is a term that does not appear in the literature but which I adopted to frame an environment that associates with different actants such as emotion, energy, pain and the body and which results in a negative outcome for the ME sufferer concerned. Whilst much work has been done that explores how spaces and places act in restorative, enhancing ways²⁶, Whimsy's data suggested the opposite. For Whimsy her flat as a physical space is somewhere where she is trapped, feels isolated and fears dying alone. The notion of a debilitating space is a way of framing how metaphoric processes transcend and connect what would otherwise be binary understandings such as inner/outer, social/individual and material/immaterial. To conclude, I draw together my discussion of central actants and their metaphoric and metonymic relations to provide the reader with a sense of the assemblage of disparate and seemingly disconnected actants that Whimsy's ME appears to be comprised of.

7.2 Whimsy's background and central actants

Whimsy is 59 years old. She was 'given away' as a baby by her mother to, and raised by, her Grandmother. Whimsy experienced 'difficulties' as a school-child. She moved several times, attending various schools, and experiencing distress because she had no parents to 'turn to for guidance'. Whimsy intimates that her education was lacking but resolved to make up for this by educating herself through art school because 'that is what [she] could do'. She now has two degrees and 'other qualifications' and has worked as a lecturer in art and design at an 'FE college teaching HE courses'. ME obliged Whimsy to give up work in 2002. She has been unemployed ever since and in receipt of benefits. Whimsy is vague on detail but claims to have been a dancer and singer, appearing on Top of the Pops and to have taught yoga and meditation.

²⁶ See chapter 3 (3.7).

Whimsy is divorced and has lived alone in a small, top-floor Georgian flat for around nine years. Whimsy feels ‘isolated and trapped’ in her flat and has worried about dying from an unspecified lung condition and ‘not being found’. Of significance is a fear of city pollution that has grown on her recently. However, she states that her isolation may be partly due to her own actions. Her flat is tidy and modern with artistic artefacts and pictures. Whimsy’s ex-husband was an ‘internationally renowned’ musician and recording artist but she left him to pursue a career in writing and stated that she was the one who provided the financial support for the early part of their relationship. She is convinced her husband had been ‘siphoning’ money into a secret account for many years.

Whimsy describes being prone to illnesses and infections through and beyond early childhood. This is conflated with a generally ‘weak’ constitution, which she has ‘fought’ to overcome.

Having provided a pen-portrait of Whimsy, I now describe the central actants in her ongoing experience of ME. Although there are many other actants, the ones I have selected convey the disparate nature of what can be described as an actant, such as material objects, people, places and emotions.

The first actant is Whimsy’s **unreliable mother**, who ‘tried to abort’ whimsy before she was born and gave her away at birth, perhaps because Whimsy was ‘ill’, her mother ‘couldn’t cope’ or ‘was post-natally depressed’. Whimsy’s Mum subsequently had five other children who she kept but Whimsy was told they were ‘cousins’. By age 11 she suspected the truth and felt alienated and an ‘outsider’. Whimsy states she can never be confident of the veracity of what her mother tells her, even of the illnesses that Whimsy suffered as a child. Yet she builds on these illnesses the notion of an inherent weakness that she has always strived to overcome and to ‘achieve things’. This is partly responsible for her ‘overly energetic’ approach to life which ultimately contributes to ME. Indeed, Whimsy explicitly identifies herself as having been a perfectionist but that she ‘wouldn’t have known [she] was a so called perfectionist. It was just the way I did things.’ It was other people that brought this to her attention. Whimsy’s perfectionist nature reflects research that suggests ME sufferers exhibit a disposition towards over-expenditure of energy related to achieving perfectionism.²⁷

²⁷ See for example Courjaret et al. (2009); Deary & Chalder, (2010); Fukuda et al. (2010).

The second actant is Whimsy's **grandmother**, who raised ten children of her own and had lost her eldest child, her husband and given birth to Whimsy's mother in the space of three months, resulting in a 'nervous breakdown' and being 'hospitalised for over a decade as a result'. Her grandmother was delusional and lead Whimsy to believe that Whimsy was the 'rightful Queen of England' and 'would ascend to the throne'. Whimsy did not fully dismiss this notion until she was a teenager.

The next two actants appear as absences. The first is Whimsy's **father**. Whimsy did not mention her father at all in our first meeting. In the ANT spirit of 'following the actor', I fed this back to her in our second meeting, whereupon she was silent for ten seconds and then, in a choked voice, said 'we will have to move away from that'. He is not mentioned at any other point throughout the data set but clearly has had, and continues to have, an effect on Whimsy.

The second absence is explicitly a **traumatic event** that Whimsy suffered at an unspecified age as a child. Whimsy associates the traumatic event with her 'first out of body experience'. She has ongoing out of body experiences, suggesting the childhood event is still present for Whimsy in a displaced form. She states that she cannot talk about it in her own home. Talking about it reactivates it and her practices of Buddhism, meditation and breathing are designed to help keep the traumatic event in the past. Whimsy states that 'intellectually' she knows the event is in the past but the negation of this is that affectively the event exists in the present.

The **collapse** is an actant which Whimsy deems a 'triggering event' to ME. She describes the 'collapse' as an event which involved witnessing one of her students screaming and banging her head on a desk in a crowded class at the FE college where Whimsy taught art and design, causing Whimsy to 'freeze'. This reactivated the experience of a neck injury she had sustained nine years previously as a result of a car crash. The triggering event is described in conjunction with Whimsy already suffering a viral infection and being in an overworked, stressful environment with unreasonable demands made of her.

Whimsy's **neck** is an actant. One night, 9 – 11 years before the 'collapse', Whimsy was taking out a 19 year old girl for the evening. This girl is described as 'like a surrogate daughter'. Whilst Whimsy was barely moving, her vehicle was hit by another car, driven at around 75 mph by a 'boy'. No one was killed but Whimsy injured her neck. She contextualises this crash by explaining how, six months before,

she suffered an ectopic pregnancy. At that time her doctor had told her not to drive. The significance that Whimsy points out is that when the crash occurred she had made a decision to drive when she should not have.

Michel; Whimsy's mentor on her Master's writing programme. Whimsy embarked on a writing career in 2000/01. At this time she divorced her husband and took a sabbatical to attend a Masters programme in writing. According to Whimsy it was designed for Oxbridge graduates with 'starred firsts'. Whimsy states that this was a 'fantastic achievement' for someone with her 'background'. On this programme, Whimsy had the 'Poet Laureate' as mentor. She establishes the credentials of Michel by stating that in France he was awarded the 'equivalent of the Nobel Prize' for literature and that he was a 'great humanitarian'. People told Whimsy she 'was trying to do the impossible' but only Michel encouraged her to achieve what she had set out to do. Whimsy carried on corresponding with Michel for a year after the programme finished. He attended her birthday party in 2001. Of this she states that he was a 'virtual recluse' but that they 'managed to get him out of his shoe box'. In 2002, again on her birthday, he died in a car crash. Whimsy states:

'Sommmeething (sic) was triggered. That coincidence the shock of that, the ending of something. The double death in a way.'

The implication of a second loss coincides with the onset of her ME and in the same year as her 'collapse'. However, Whimsy does not expand on what the first death of the 'double death' applies to.

The **wooden peg**.



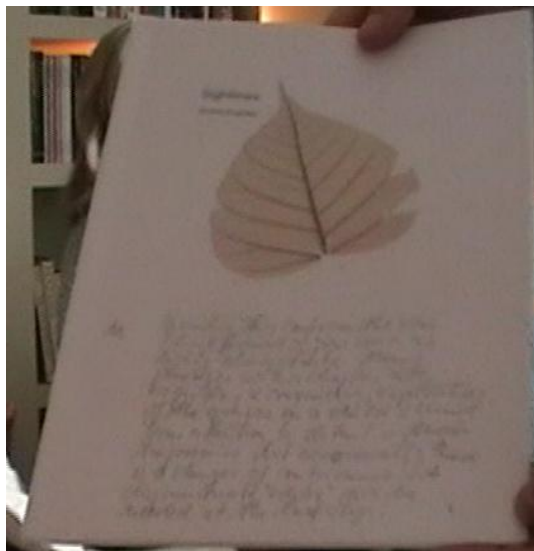
On her writing course Whimsy submitted a story about a grandfather who used to whittle pegs in the autumn. The reference was to a Grimm's fairy tale. Michel noticed this because 'it resonated with him' and that they 'had imagined something similar'. He was an Austrian raised in Switzerland with a German father who would not talk to him about wartime persecution of Jews. As he grew older Michel realised that he 'had to look into the story or reality of that' to find out what his 'heritage had left him'. As Whimsy puts it:

'Some kind of scar on his character because his forefathers had been involved in this and they're trying to cover it up.'

The implication is that Michel was also haunted by a past he was not in control of. In her story there was a row of wooden clothes pegs on a washing line. A child was noticing these hand-carved pegs and, as such, each one looked identical but they were in fact all different. Whimsy explains that their 'conditionality' is different. The pegs represent 'the act of closure' and 'as a metaphor of something that connects, holds and separates'. Michel noticed this. Thus, the real object that Whimsy showed me was a hand-carved wooden peg in a glass display case, with a handwritten inscription that reads:

"Here's a solitary peg. A batch more is being dispatched from Switzerland."

A further actant is the **writing front cover**.



This is a piece of white A4 paper with a handwritten comment about Whimsy's written work from Michel and a stuck on leaf. It is involved in the same work as the peg. The comment is encouragement from Michel and the paper itself is important because

‘[Michel’s] hand is there’. She states that if there was a fire, the peg and the paper are the only two things she would attempt to save.

Prior to my visit Whimsy had put this case and the writing cover-sheet on a chair under her table and out of my view. She produced it when I enquired about objects and as she hands them to me she is laughing and giggling. But as soon as she handed them to me she covered her face with her hands and when she eventually removed them she had tears in her eyes.

Breathing is an actant appearing explicitly throughout the data. Over the last few years Whimsy began to experience breathing difficulties. She had several investigations but is ambiguous as to what is wrong; an x-ray revealed ‘something tangible’ but that something is ‘not quite asthma and not quite bronchitis’. Whimsy uses meditation and yoga to help regulate her breathing. She connects the issue of breathing to city pollution and being in her flat.

Whimsy’s **flat** is an actant. Whimsy purchased a top-floor Georgian flat after her writing course to ‘shut herself off and write’. However, she has increasingly felt trapped in this flat and unable to move, especially post-ME. The entry buzzer does not work and she feels isolated. The air in the city is polluted and she cannot get outside. She fears ‘dying alone in the flat and not being found’. Whimsy explains that many fellow residents complain about ‘pollution’ in the air.

7.3 Using metaphor and metonymy to explore the associations between actants in triggering events

In this section I explore Whimsy’s narration of triggering events by adopting the underlying premise that actants exist in association with each other and become displaced across time and place. Noticing and conceptualising these displacements was achieved by using the metaphoric and metonymic framework I described in chapter five. The key feature of metaphor and metonymy to bear in mind is that it cannot be presumed that a metaphor or metonym represents a simple one-to-one mapping of an idea in one domain to that in another (Kimmel, 2010).

Thus, scrutinising the data for causal metaphorical and metonymical relations is inadequate. Instead, the task is the imaginative linking of concepts that might be metaphorical or metonymical and then searching the rest of the data for similar instances of the same metaphor/metonym, related conventional or novel metaphors or

figurative comparisons and determining whether the emerging associations are commensurate with the connections between actants in an ANT sense. The aim in a simplified sense is to be able to arrive at the notion of an assemblage where the actants involved can be observed in association directly in the data and also in terms of metaphorical or metonymical relations.

In the following extract from Whimsy's data she is describing what she considers to be the event which preceded her ME. I approach this event as an actant and refer to it as the 'collapse'. Whimsy describes the event accordingly:

'And I couldn't actually make any contact (0.25) with this girl who was screaming. I knew who it was and I was full of concern. But (0.75) um (1.0) the whole situation just got out of control. And I () apparently what happened was I () what seems to have happened was I () froze () in () a state of trauma () and I triggered off a neck injury that I () had from a car crash I had a near fatal car crash.'

She goes on to state:

'And then () there I was driving a car with two young people. You know () other people's children and I nearly killed them. Umm () so () may I () kind of think that there was um () a link between the girl in the studio who was also about that age and my () concern for her. Not being able to do anything about it. On top of my ha ha exhaustion and umm () mostly () pressure from umm () management. To you know kind of () perform miracles. You know () with no () funding.'

In the account of the 'collapse', above, there is a literal and metaphorical inability to make contact with the girl. Beyond the affective content and intensity of these recollections for Whimsy, I noted a compounding of events. Whimsy has a tendency to amalgamate events in her narratives that do not immediately seem connected. There are several instances where this process is signified by her use of the term 'on top of', as in the extract above. I interpret the way that Whimsy compounds events as more than one metaphoric or metonymic relation becoming activated. This brings to mind Montana Katz's (2011) assertion that several metaphoric processes can become complexed into one object or process. The manner in which metaphors complex with each other can be conflicted and contradictory and this might be reflected in the way that Whimsy's narrative or experiences can often feel compounded and confused. It is for this reason that analysis cannot proceed with the notion that metaphorisation is a rational, discrete, causal and easily identified process.

In the following extract, Whimsy has told me she was suffering a virus around the time of the ‘collapse’ and has had susceptibility since childhood:

J: So you you've () been catching viruses since childhood?

W: Not viruses. But things like umm () what am I saying? Scarlett fever on top of chicken pox on top of someth- I don't actually remember this but that's what I'm told. That I was () kind of sickly. Umm (3.0) or rather weak. I was () weak. Ha ha.

J: Yeh.

W: A bit bit of a wimp ha ha.

Beyond compounding illnesses, this extract is interesting because of the way that Whimsy uses the term ‘wimp’, which implies a character flaw on her part. There is an affective movement in the penultimate line where she shifts from being told she was weak to self-identification as weak.

In this extract, Whimsy is explaining that she fears being found dead in her flat, apparently from breathing difficulties:

‘And last winter when there was lots of viruses and things around I felt for the first and only time that I would die. In this flat umm. And for various reasons one of which was the entry phone () wasn't working. I don't know if it was when you came last. Which (1.0) if you live on the top floor can be sort of slightly concerning. And so that seems kind of a normal response to me. And part of me also wonders how much of it is in my mind and () you know whether it's my mind () not sending the signals to my body to move and if it's not, why is it not. So it's a kind of (2.0) it's almost like a syndrome on (laughing) top of a syndrome.’

In this extract, Whimsy compounds viruses, with a broken answer phone, fearing dying [as a normalised response] and worrying whether her mind is implicated. I connect this fear that her mind is in question to my observation that Whimsy often requires others to validate her experiences.

Events in the external world for Whimsy are often conflated with the implication of personal responsibility and, most importantly, an inability to remember with clarity what has happened or the reason it happened. In this vein Whimsy's data reveals many instances of a need to be validated by others. For instance, she describes validation of her ‘personality’ by an occupational therapist who establishes her collapse as PTSD. Friends and ‘other people’ tell her she is a perfectionist and her mentor, Michel, establishes her in terms of ability but also as a worthy person. It is

significant that the peg and cover page were shown to me because these embody Michel's validation of Whimsy's potential. My affective notes state that I felt Michel was a surrogate father-figure for Whimsy but also that there was an 'attraction' to him from a romantic perspective. In contrast to those that validate her, Whimsy constructs a GP as 'not knowing' what is wrong with her and this mirrors and validates Whimsy's own confusion about ME. My affective notes reveal that as the research progressed, I developed a feeling that Whimsy did not know who she was, reflected in a struggle to establish a coherent sense of self.

In this final example, Whimsy has been explaining her perfectionist, 'buzzy', 'speedy' character to me:

'I was I was I hadn't realised it myself but () from time to time people would say: and of course you're a perfectionist. Umm (1.0) and I have I think it's probably relevant to say I didn't go to school very much. I was in distress an umm () didn't have my parents I would be sent to another school and another school so I went to veeery very many () different schools. And have got hardly any memory at all of being at school. But when I was old enough to () I decided that what I had to do was educate myself. So when I got into art school, which seemed to be not so difficult, it was kind of what I could do. Because I was curious about everything. Then I on top of that () started taking courses in sort of literature. And then went on as a mature student to do my () degrees () and I got starred firsts and then I went to do umm another degree and worked with the poet laureate so in some ways I achieved what I set out to do.'

The first line shifts narrative from perfectionism to not being at school and distress. This implies an affective movement has occurred for Whimsy. Whimsy then narrates how she took courses on top of other courses. Taking these courses appears to offset her experiences at school but the central feature is her lack of parental support. The implication is a metaphorical relationship between what she describes as perfectionism and lack of parental input which becomes displaced into a later desire to succeed academically.

Overall, the manner in which Whimsy compounds events brings to mind Freud's notion of condensation. This is a metaphoric process where the properties of objects or persons in one domain are conveyed as a single subject in a different domain that is not literally equivalent. Interestingly, condensation represents repressed, traumatic material; repression is a defence mechanism whereby traumatic events are unconsciously forgotten, so as to defend the ego from anxiety (Freud, 1900).

What I take from this is that analysing data such as Whimsy's requires techniques that go beyond a rational interpretation because it is difficult to account for the shifts in narrative, especially as there exists a complex conflation of past and present. Using the notion of metaphor to scrutinise data provides a means of connecting the moves that Whimsy makes from disturbing events through her narrative to pressure at work and intimates the metaphoric equivalence between events that may frame understanding (Schmitt, 2005). What this means is that for Whimsy, events from her past which are clearly distressing have been transformed into events that are consciously more manageable. For instance, data not presented here suggests Whimsy identifies with the girl in the studio and represents a metonymic equivalence between their helpless situations. When the girl started screaming, an affective movement occurred in Whimsy which manifested metonymically as a neck injury and freezing. However, it appears that her neck injury is already a metaphorical translation of other actants. Thus, Whimsy has rationalised conflated events through the metaphor of her neck.

Metaphor enables a way of understanding the relations between elements in a narrative that are difficult to reconcile or do not make obvious sense. In the case described there is no clear link between for instance freezing and the girl screaming. Neither is there a discernible link between Whimsy stating that she was a perfectionist and then shifting her narrative to describe how she did not go to school much.

Focussing on further metaphoric and metonymic aspects of her collapse, the car crash described by Whimsy involved the potential for death. Death appears explicitly in Whimsy fearing dying in her flat and implicitly in fearing her neck will break. The crash also involved Whimsy feeling guilty of causing it and her inability to do anything about avoiding the crash. Her neck is implicated directly in the crash and indirectly in her 'collapse'.

Regarding her car crash, Whimsy states:

‘And I was driving at around three miles an hour when the car was hit but it was (0.25) a near fatal crash.

J: So somebody else hit you but going...

W: At seventy five miles an hour. Yeh. But they the two passengers my passenger and the umm (4.0) the driver (0.5) were both about nineteen years old. And what I know () I didn't () quite know it then I intuited it but I know that um (0.75) it was something that (0.75) I couldn't (0.5) I couldn't come to terms with the fact that I'd lost a baby.'

There is a conflict between feeling that she had nearly killed the youngsters in the car and the way she has already established herself as innocent because she was barely moving when ‘hit’, implying her passive role in the event and this brings to mind questions about her agency. Whimsy has made a conscious association between these events but via a series of metonymic equivalents, death has become associated with her neck. I note a further compounding of events, given the narrative disjuncture between the crash and her loss of a baby [ectopic pregnancy], which again she could not be consciously responsible for and which may suggest a metonymic translation is activated. An important illustration can be drawn from this. An aim of ANT is to rethink the dichotomy of agency and structure. In chapter four I described agency in terms of:

“...the collective capacity of heterogeneous networks, in which the activities of the non-human may count for as much, or more, as the activities of humans” (Ruming, 2009; p.456).

Through the ANT lens, Whimsy’s self-conscious sense of agency that she ‘nearly killed them’ is not fully explained by the arrangement of actants that came together and which resulted in the crash and in her sense of agential responsibility. There remains something interior about that sense of agency that the ANT approach does not quite capture and yet which the psychoanalytic influence might help to retain. That is the manner in which sense has been made by Whimsy of the events and in how they appear to be metonymically related but in ways that are not immediately clear.

For example, my interpretation of a metonymic displacement between feeling responsible for the crash and the loss of a baby appears to follow a logic that makes sense in terms of an unconscious process that is simultaneously internal and external. Whilst the externalised effects of this process are visible in the data, the associations between actants remain non-representable in a way that neither a rational framework nor recourse to ANT critique of social explanations, such as the notion of ‘black boxes’²⁸, can easily account for.

²⁸ A ‘black box’ is an artefact that is taken as providing a specific function where inputs predict outputs and yet the workings of the black box are hidden (Latour, 2005). This also applies to conventionalised social explanations and knowledge which has become accepted and unquestioned as a matter of fact (Yonay, 1994).

Overall, there may be metonymic equivalence of ‘failure’ between these events and the inability to ‘perform miracles at work’. I envisage a network of metaphoric and metonymic displacements associating the ectopic pregnancy, car crash, her neck, freezing in the studio and hence her collapse. Associated with this is the post-viral fatigue that had been diagnosed *before* ME and factors such as overwork. Several situations where Whimsy is in a position of helplessness can be identified which represents a metonymic translation reprising her abandonment at birth and lack of [parental] support through school. When it comes to her ‘collapse’, Whimsy is unable to intervene and help the girl who is screaming. Neither could she intervene and help her baby nor the girl in her care in the car crash. Thus, even though Whimsy has no agency in these situations, she feels as if she does because they represent metonymic displacements of her own helplessness.

Having said this, there remains a danger of reading Whimsy’s data from the perspective of existing discourses that might attribute her ME to an ostensibly interior cause, such as her ‘perfectionist’ personality; which has become a “persistent behavioural problem regardless of [Whimsy’s changeable] social environment” (Gadd & Jefferson, 2007). This is to imply that perfectionism is indeed a quality of the person that is independent of context. Alternatively, a social cause might be posited which represents the misattunement of her early maternal environment and subsequent difficulty at school. However, there is an issue about how to characterise what a perfectionist personality is without categorising it in terms of social norms in the first place. Metaphorically re-establishing the relationship between what are otherwise taken as psychological and social explanations is a way of exploring how the social and the psychological are mutually infused in the first place.

Despite Whimsy establishing herself as striving to overcome her origins in an overly energetic and perfectionist manner²⁹, the subjective experience of being perfectionist may differ from clinical measures of perfectionism and approaching perfectionism as an abstract category belies a complex arrangement of many subjective factors. Objectifying perfectionism implies a causal relationship with the individual concerned, which can be measured as an ongoing, stable effect. This decontextualises

²⁹ ‘Perfectionism’ is contested in terms of whether it represents a uni- or multidimensional construct; see for example Shafran, Cooper, and Fairburn, (2002); Hewitt et al. (2003). For descriptions of the clinical assessment of perfectionism see Fukuda et al. (2010).

perfectionism and overlooks its particular manifestation and results in the focus shifting away from the processual and dynamic associations between things. This results in an illusion of deterministic relations.

In Whimsy's case, there appears to be a strong association between her infant environments, lack of care as she understands it and failure at school. Her perfectionist personality is situated in a particular way which may differ from another sufferer's perfectionism. For Whimsy, perfectionism is about 'not having had guidance on how to act', which resulted in her 'not knowing where to draw the line' or 'where the boundaries were' and that she felt she needed 'stabilisers' both physically and affectively. She describes this in a range of contexts, for instance:

'How do you know how to do anything at all? How do you know (0.25) um table manners? The things I kind of exhausted myself with learning. Ok. So I would like to have perfect table manners. So I now have perfect table manners. Anyone else eats their grub and they don't think about it.'

The significance is that Whimsy understands her perfectionist personality through a set of specific experiences that were exhausting because she did not know when to stop. Rather than objectifying perfectionist personalities, using metaphor and metonymy as the basic currency of translation between various domains is what allows associations to be traced as a subjective process that involves disparate types of actants and resultant actions and identities.

Concerning ME, establishing actants in terms of metaphoric and metonymic relations is vital. I moved away from understanding ME in terms of an inherently causal model where Whimsy was overworked, stressed and post-viral. Instead, I envisage Whimsy's ME as an assemblage of disparate actants, including her early childhood experience.

However, one problem is how to account for specific metaphoric and metonymic processes and why one metaphor becomes salient over another, given that metaphors often overlap and co-occur (Benczes, 2011). In Whimsy's case why was the neck injury triggered in the studio and why did it invoke a translation for me that involved death? There are two issues here.

One is how the researcher arrives at a particular metaphoric understanding and the other is how the ME sufferer arrives at an understanding. With this in mind Stern (2001) notes that metaphor is sensitive to context in a linguistic sense. Salient features

of the immediate linguistic environment influence metaphor choice and use and this will reflect in the way that metaphors and association became activated between Whimsy and myself during our discussion. Before I could arrive at ‘death’ being metaphorically present and using that to think about how actants were associating, I had to check that it could be substantiated in the data and that it fitted the context at the moment of translation around Whimsy freezing in the work studio. Secondly, my understanding needed to fit with Whimsy’s descriptions of her experiences, which it did. This is reinforced by her explicit references to death at various times.

This section has outlined how I used metaphor and metonymy to explore the associations between actants that comprised an ME triggering event for Whimsy. In the subsequent section I use the notion of metaphor and metonymy to describe how ‘energy’, a cardinal feature of ME, can be understood in terms of metaphorical translation of the way that actants associate. I describe the moves between energy, an already abstract construct, as a conflation of physiological, psychological and material actants such as Whimsy’s neck and real and imagined others.

7.4 Energy in metaphorical terms and the problem of conflation

The issue of energy and fatigue is important both in terms of sufferers’ experiences of ME and psychiatric and biomedical concerns with characterising and managing ME.³⁰ Biomedical research does not address the subjective use of the term ‘energy’ and the conflation of neither psychological and physiological aspects, nor what it’s idiosyncratic deployment as a term means. However, a subjective and conflated use of energy can be rethought in terms of metaphorical and metonymical equivalence. This enables the tracing of connections between apparently disparate actants to arrive at a psychosocial understanding of what energy is doing in Whimsy’s account.

In these extracts Whimsy understands energy as:

‘It’s about being able to wake up in the morning and not have a resistance in my neck to movement. So if you like it’s the freedom to wake up and get up and go. That seems to me. And then to have a consistent flow. That I get sort of blocks () as though the energy must be there somewhere. Trapped.’

³⁰ For discussions of the relationship between energy and managing routines to avoid boom/bust see for example Anderson and Ferrans, (1997); Ware, (1998); Hart , (2000); Jason, Muldowney & Torres-Harding, (2008); Soderlund, Skoge and Malterud, (2000); Jason, Benton, Torres-Harding & Muldowney, (2009); Goudsmit, Nijs, Jason & Wallman, (2012).

This is a quantified, materially-orientated conceptualisation of energy. Whimsy goes on to state:

‘Do you remember when you left last time () sorry not when you left. The last question you asked me last time was about energy. You asked me what I meant by energy. And I didn't know how to answer that question. And partly it's about I've tried to think about it in so many different ways and kind of wracked my brain until I () was not kind of coming up with anything anymore. But the thing I remembered or the thing I could point at () that there was evidence for () is the () um () neck condition that I wake up with ha ha every morning. I then have to work my way around before anything starts happening in my lower body. Cos the problem's there and all my kind of circuitry it feels like it's not working until I start () manually () moving my head. [...] some days I would have to stay in bed. But that was a physical reason for not being able to get up. But if you like the x-rays are there to show if you like it's a mechanical problem. That's causing that. [...] But I was trying to answer your question () struggling with how I could explain this thing about energy () um () when actually I could have said something like: okay () I wake up in the morning and I feel like a dead weight. I feel like there's no energy flowing through me. And for energy to start flowing I somehow () have to manoeuvre myself around () and start.’

In reference to the first extract, the negation of ‘freedom’ is being ‘trapped’. Because the energy is trapped, Whimsy is trapped. ME equates with blocked energy flow and whilst she implicates both mental and physiological effort, Whimsy associates these with the issue of her neck. My affective notes with regard to this moment read:

Perhaps the subsequent laughter after this statement again represents that she is unable to see the neck in metaphorical terms and instead it is identified metonymically.

The second extract suggests that Whimsy is objectifying her body, in that she refers to ‘circuitry’ that will not work, implying that a mechanical metaphor involving flows of energy is being called upon.

Whimsy also states:

‘W: Yeh. Well according to the um first consultant I saw () that was then called post viral fatigue syndrome () everything could be accounted for by the fact of this () neck injury. Um () that would deplete me of energy so much so that some days I would have to stay in bed. [...] But I had an experience of waking up and feeling that I literally couldn't lift my head from the bed. [...] but all I could think of was this must be some kind of mental

thing that was pulling me down. But if you like the x-rays are there to show if you like it's a mechanical problem. That's causing that.'

In this extract, Whimsy appears to mobilise her neck in two ways. Firstly, the manner in which it becomes the the thing that accounts for PVFS and secondly as evidence that she does not have a 'mental' issue which underlies ME. The X-rays validate for Whimsy that it is an objective, mechanical problem. In other words, the neck *really is* the problem. She consciously equates ME in terms of a block of something called energy by her debilitated neck.

There is a relationship here to psychoanalytic ideas where unconscious anxiety that cannot be verbalised or expressed symbolically manifests as an apparently [to the sufferer] disconnected somatic symptom (Elisha, 2011). For instance in the contradiction between Whimsy's fears that her neck will break and that she has been told by physicians it will not break. According to Montana Katz (2010) what is experienced as real reflects the metaphoric processes that give rise to experience. It is interesting to reconcile this with standard ME discourse because it is not easily accommodated, given that biomedical approaches adopt a rational framework and reduce psychological symptoms to biological causes and because ME is described as an heterogenous and contested condition (Karfakis, 2013).

Because Whimsy spent periods of time in bed, due to her neck, her friends began to suspect depression as the cause. Whimsy also began to wonder whether this was the case but concluded it was not because she is 'the opposite of depressed'. She also explains that once her neck started to move there was an 'unblocking of energy' and she was then able to function. She states that even her post-viral fatigue can be 'accounted for by her neck'. The translation of various actants including the collapse, the car accident and post-viral fatigue are mobilised metaphorically by Whimsy and translated as her neck. The neck is a visible and tangible sign of the conscious and unconscious anxiety that is associated with the other actants and enables Whimsy to make sense of her situation and experiences. The conflict inherent in this arrangement is that Whimsy cannot fully dismiss that her neck might actually break.

In the previous section I noted the saliency of 'death' either implicitly or explicitly in Whimsy's narrative. Metonymically, with phrases such as 'I feel like a dead weight' and 'I feel like there's no energy flowing through me', Whimsy is establishing the relationship of 'energy' with herself as 'dead'. The implication is that until she can

physically move her body, primarily her neck, there is no energy. For Whimsy to be alive she has to move and this failure to move, to live, is now embodied by her frozen neck.

Rather than assuming energy is a mind or body phenomenon, Whimsy appears to relate to energy as a metaphor that enables her to articulate and experience the relationship between her neck, ME and actants such as the collapse. Thinking about energy as a metaphor that enables the sufferer to understand their ME is a different perspective from one that establishes energy as something objective and which the sufferer can have a deficit of. Energy is therefore in itself metaphorical and this goes beyond the simple conflation of psychological and physiological aspects. It can also be seen as a flexible discursive resource which means different sufferers can deploy the concept in different ways; a notion in keeping with previous research.³¹

Issues around energy were a feature of ME for all the sufferers I worked with. For instance, John made explicit the conflation between physical and psychological aspects of energy and yet for him energy was metaphorically translated into paper items such as letters, flyers, clippings and pamphlets which he collects. John's rational reason for hoarding such items was so that he could have sufficient information to make decisions about things like internet providers. However, he was distressed by the build up of paper and not making decisions and he woke up in the mornings feeling overwhelmed and 'depleted of energy'. His flat was beginning to overflow with paper and his recourse was to escape into town every day. Whimsy and John both suffer ME that implicate both energy and their flats albeit in different ways.

In the next extract, Whimsy is talking about how yoga 'heals' and this represents another actantial association to energy and also to breathing, which she has identified in terms of her asthma-like symptoms and fear of pollution:

'If you're in pain () and you feel like you haven't got much energy () and you feel () you identify with illness () then what's going on is kind of in your head (1.0) and this () this kind of syndrome it's either coming or it's there or it's leaving. You know that's why it's a syndrome isn't? So () a lot of your time () because you don't feel very strong and you don't feel you can go out and do things and lead a normal life a lot of the time you're kind of trapped in your head. You know I said I sometimes feel trapped in this flat? Well part of that is sometimes I feel if I go out I haven't got the energy to get back again.

³¹ See for example Horton-Salway (2001, 2004, 2007).

So all that is part of the syndrome. But when you do physical exercise you're focussing on the external aren't you? And of course it's your body. But you're able to almost come out the back of your head into the front of your head to see what's () to focus on () um () one of the things is breathing. And that helps.'

Whimsy metaphorically locates depleted energy in her head. A metonymic translation becomes activated between being trapped in her head and being trapped in her flat and hence the relation to 'energy' and ME. Towards the end of the extract Whimsy appears to differentiate between her self and her body because the 'external' is 'your body' and she is almost able to 'come out the back' of her head. Elsewhere, Whimsy describes how meditation grounds her and 'literally' connects her to the earth. It appears that the equivalence between flat and body and being trapped is metonymical so that the relation between self and body is displaced into her flat. This interpretation is reasonable, given that Whimsy proceeds with:

'W: But (1.0) well not but () and () energy produces energy. Doesn't it? It's this thing of kind of being stuck. Inside a thing that is not working properly. That of course causes distress. Causes alienation.

J: So do you feel stuck inside a body that's not working?

W: I have yes yeh. So that's what I was stuck with. So () that's had some effect. That's made me feel trapped. And interestingly the term the consultant used on the letter was nerve entrapment.

J: So that entrapment stuck with you? It had some significance?

W: Yeh it felt like entrapment it feels like being locked into something.'

By stating that she is trapped inside a body implies that Whimsy identifies 'self' as something separate and yet internal to her body. She highlights the significance of the consultant's statement about 'entrapment'. The terms 'trap/trapped/entrapment' thus appear to hold together certain metaphorical associations for Whimsy. There is a metonymical relation here between a body that does not work and a flat that has trapped her due to an intercom that will not work. Perhaps the alienation Whimsy feels due to her compromised body is also reprised by feeling alienated from her flat. This interpretation is significant because it illustrates a translation between the domain of the material world and the inner world and how a place becomes entangled with ME, as I discuss below.

However, Whimsy's deployment of energy as a concept may not be entirely available to conscious reflection and is better understood as reflecting individual and social processes that are not easily articulated in either register. On the other hand, what

Whimsy says about energy reprises familiar themes from discursive and phenomenological work. The deployment of the term energy enables Whimsy to construct a legitimate version of ME and thereby helps in the struggle to make sense of her experience. Energy as a term informs a social discourse of ME because it is intelligible and can be deployed as a common cultural object (Froggett and Hollway, 2010).

In summary, the purpose of this section was to explore how energy and hence ME is understood by Whimsy in a way that contrasts with biomedical approaches. I used metaphor and metonymy to trace the associations between energy and how Whimsy deploys a particular understanding that involves mechanical metaphors of the body and bodily processes. Whimsy equates ME with an energy flow that is blocked by her neck. Her neck is associated with the trauma of a car crash and reappeared explicitly at the time of Whimsy's collapse. Whimsy is alienated from her compromised body and this reflects her relation with her flat. In the next section I pick up the relationship between Whimsy and her flat and discuss the significance of the associations between people and material environments from a metaphorical/metonymical perspective.

7.5 Debilitating spaces and the maintenance of ME

Having described how I think about the relations between various actants in Whimsy's experience of ME, this section focuses on environments as both a physical place and a psychosocial space that may play a part in maintaining ME. Besides Whimsy, I briefly discuss John and Hannah and their relations to specific spaces.

In chapter three I outlined the relation between health and environments in terms of enabling and restorative functions. However, it is not clear which specific aspects of place should be regarded as enabling'. Some literature focuses on the material properties of place (Steinfeld and Danford, 1999) whilst other literature stresses its psychophysiological or social aspects (Korpela et al. 2008; Cattell et al. 2008). Despite some authors acknowledging the benefits of thinking relationally about things, people and places they tend to advance a notion of how health can be maintained or restored via the types of resource that become mobilised by or converge in a specific place. In contrast to the idea of enabling and restorative places, for Whimsy, John and Hannah, the immediate environment of their homes appeared to function in a debilitating way that was highly entangled with how they experienced and made sense of ME. To

capture the way that an environment can have a deleterious effect as part of ME I use the term *debilitating space*.

The notion of a debilitating space provides a frame for exploring physical environments where different actants such as emotion, energy, pain and the body interact with specific material places in non-causal ways. This is in line with Cummins, Curtis, Diez-Roux and Macintyre, (2007); p.1825) who state that despite renewed interest in how space and place shape health:

“Empirical research has relied on rather conventional conceptions of space and place and focused on isolating the “independent” contribution of place-level and individual-level factors”.

Cummins et al intimate the same, implicit focus on assumed causal structures that appear to characterise how ME is understood from biomedical perspectives.

My argument is that a place can be explored as part of an assemblage of the experience of ME. Whimsy’s flat is a debilitating space that is fundamental to her experience of ME. However, it is not the flat in itself as a certain type of space that is the problem. Instead, the materiality of the flat is involved in the translation of highly conflicted and entangled actants such as the split between Whimsy’s body and self, energy and her neck and real others. From the ANT perspective, the flat held specific potentialities that have become displaced into specific identities and from there as part of Whimsy’s understanding of ME. For instance, the broken intercom, the fact that the flat is on the top floor, has poor air circulation and is in a city became potentiated in terms of the alienation that Whimsy feels to her body.

Most significantly, the flat is a space from which the traumatic event is consciously barred. The degree of success of this disbaring is questionable. Whimsy has come to understand, via the displacements between these actants, that the flat is no longer a place where she can create and be happy. The flat is a prison that metonymically reprises her relationship with her body and with other, explicitly discussed, traumas.

I have briefly outlined above how John’s flat associates with paper in a similar manner such that he has to literally escape his flat everyday, which like Whimsy’s is small, top floor and Georgian. John was an officer in the RAF with status but had to retire due to ME. John describes his flat as reflecting ‘a loss and lack of status’ and this means that he is uncomfortable inviting people into it, especially his eleven year old son who lives

in another town. The size of John's flat was a potentiality that manifested as John's failure and he does not want his son to see him as a failure. Because of what is in the flat [the piles of paper he hoards] and what this represents to John, he is constantly 'overwhelmed'. The flat is a constant reminder of 'how he doesn't want to live' and 'what needs to be done'. Overall, John's flat is a space where he is worn down and fatigued.

A further sufferer, Hannah, who is twenty five and lives with her mother also demonstrates an entanglement between place and ME. Hannah's house metaphorically represents a safe haven where ME is kept in abeyance and therefore more in line with notions of enabling and restorative places. Hannah's ME symptoms are entangled with agoraphobic symptoms and hence literally outside her house is anxiety, insecurity, alienation and otherness. Significantly, this represents a split where the environment outside the house is explicitly associated with Hannah's ME and where her fatigue is 'worse'.

Whimsy feels trapped in her flat and does not have the energy to escape it and fears dying alone there. In this sense, Whimsy, John and Hannah experience specific environments in a way that appears to be intrinsically entangled with their experience of ME. But this is not the same as saying the environments are causing or maintaining ME. Rather these specific environments are instead part of an assemblage which amounts to the ongoing experience of ME but from which ME is inseparable.

In summary, Whimsy's flat appears to be involved in the translation of entangled and conflicted actants such as the split between her body, sense of self and energy. As such, the flat as a physical space has become a defining feature of Whimsy's ME experience, symbolising specific metaphoric associations such as being a 'prison' and 'trapping' her. I have described her flat as a debilitating space; a term which attempts to capture how certain environments can become entangled with ME and hence impede recovery in ME sufferers.

7.6 Social relations and imagined others

Whimsy's neck is a central actant in her experience of ME that appears to have made itself indispensable (Callon, 1986). In the present section I discuss how Whimsy's neck mediates and in fact limits the potential for her to have successful romantic relationships with others. In doing so, I emphasise how real others become imagined

(Frosh, 2002) and become implicated in Whimsy's experience of ME. This section illustrates that the boundaries or effects of ME are insidious in that a compromised romantic relationship and what it entails would not immediately appear connected to ME. Identifying the idiosyncrasies of each sufferer's ME experience is thus important.

In the following extract Whimsy is explaining how her compromised neck has an effect on her ability to have a romantic relationship, ostensibly through fear that if someone hugs her neck might break.

W: So it's had an effect on a () romantic life. If you like. Because I'm very anxious.

J: Say some more. (1.0) How are you making the jump to () limited movements to anxiety to () romantic relationships?

W: Well () okay okay. Um (3.0) I feel very anxious if someone puts their arm around me. When friends come to- () sorry () not friends. When male friends come towards me to kiss me as a gesture of friendship. Or () maybe not necessarily friendships. Maybe something more than that () I have to withdraw. So all the time I'm guarding this (2.0)...

J: Neck area.

W: Yeh yeh. All the time. Um () a friend came this afternoon and I've known him for twenty five years but I still have to back away () because he is a big person who's got a strong grip and wants to hug. Um () you know a friend. And I can't bear that cos I feel like my necks gonna break. After all this time and I know it's not gonna break. Um I've seen a scan () if you like () to prove () that it's not gonna break. But it doesn't mean it doesn't feel like it. The doctors have sat me down and said () it () it looks like () from where you are if you do that [moves her head side to side slightly] it feels like it will break but I can assure you it won't because of this and that.'

Whimsy expresses conscious anxiety about 'romantic life'. The three second pause suggests she is having difficulty accessing a domain that involves romantic relations and this represents a point at which metaphor and metonymy needs to be used to consider what such relations may involve, for instance love, caring, trust and so on, because doing so provides a further means of exploring the data.

Whimsy is experiencing difficulties acknowledging affectively what romantic relations might involve, reflected in the way that she conflates platonic and romantic relations and then has to correct herself. The manner in which the neck is implicated is interesting because her reticence to name the neck is apparent. It is when I name it for her that the narrative moves forward. However, despite making explicit the romantic connection to the neck, Whimsy struggles to talk about her male friend in this light and

works hard to establish him as ‘you know a friend’. I also note that she adopts a passive stance towards this friend in that ‘he wants to hug’. My affective notes at this point reveal that I experienced Whimsy as helpless. The final three sentences imply that Whimsy fears her neck will break despite seeing evidence to the contrary and this suggests a failure to experience her neck injury as a discrete event that happened in the past, in other words a metonymical displacement from past to present has occurred; Whimsy’s neck has become the real problem for her.

Borbely (2009) describes a past traumatic event that is unconsciously repeated but in an unrecognisable symbolic way in the present as *negative metonymy*. This term implies that whatever is symbolically appearing from the past feels like it is occurring in the present and this means that the individual is unable to re-structure past unconscious memories in light of present experiences. Thus, what is activated when Whimsy encounters a possible romantic liaison is symbolised in anxiety that her neck will break. Applying the ANT framework to such an arrangement is useful because it enables the tracing of associations between the neck and other actants that at first may appear unconnected. Moreover, this also highlights how actants become complexed together. Whimsy’s neck is thus only part of the picture.

Exploring Whimsy’s narrative using metaphor and metonymy illustrates how antecedent incidents are translated into real social relations and from there structure real interactions because the anxiety that her neck represents is preventing Whimsy engaging with someone romantically. However, it is not immediately apparent what the association between specifically romantic relations and anxiety is, but it is apparent that her neck situates that anxiety. For instance, it is equally possible that Whimsy fears that a romantic interest will actually love her, as much as she fears being actively hurt or rejected. It is also possible that Whimsy fears she is unable to love another. However, rather than hypothesising about these alternatives, the focus is on what can be determined from her neck and what she says about it.

To elaborate on the relation between Whimsy’s neck and romantic relations requires further scrutiny of the data, for instance to determine if there are consistent metaphoric relations between her neck and male relations in other contexts. Because Whimsy conflates ‘romantic’, with ‘friend’ and with ‘male’ and has to withdraw from anything more than friendship, it would be useful to go back to the data to determine what

actants associate around friendships, romance and relations to establish whether anything is mobilised in line with what I have described about energy.

That ME affects social relations is a widely reported effect, usually understood for instance as a rational line of causality, for instance that ME involves unpredictable fatigue, fatigue inhibits activity, socialising requires activity therefore ME inhibits socialising (Dickson, 2004). In contrast, identifying actants such as Whimsy's neck provides a means of following the translations between particular and subjective bodily aspects and other actants. A reformulation particular to Whimsy might entail these displacements: her 'collapse' metonymically translates a neck injury from a car crash, her neck blocks energy flow in her body, this restricts her activity, she fears her neck will break and avoids romance and this assemblage *is* ME. However, from the ANT perspective, networks do not exist as small, discrete entities and this necessitates following actants as far as possible to establish further associations.

7.7 Expanding the network

Following the actant of Whimsy's neck leads to other actants such as a traumatic event from childhood which itself associates with out of body experiences (OBE), which Whimsy has experienced since a child. Whimsy does not talk about this event in her flat and, as such, it was present in her narrative as an absence. But perhaps this event is neither entirely available for Whimsy in a conscious sense.

For example, Frank (1995) characterises traumatic experiences in terms of 'chaos narratives' which sit behind speech but are incommunicable because there are no words available to tell them, which points to the impossibility of representing or sharing such experiences with others. From a Kleinian perspective Minsky (1998) claims that attempts to find words for traumatic experiences are split off and projected and are thus unavailable to description. Thus, the significance of Whimsy's traumatic event is that it appears to play an actantial role in how she manages aspects of her ME. Despite it appearing as an absence, its effects as part of a network can be detected in the identities and actions that result in the actants associated with it.

OBE metaphorises the split between Whimsy's body and self. She uses meditation and breathing practices to ground her in her body and keep the traumatic event in the past. These actantial practices also enable energy to flow and the neck is central to this. For instance, Whimsy explicitly states:

‘But the breathing is part of the yoga. And it seems to me () in terms of things being connected () um the flow () that seems to be blocked () in this condition () that’s what ME is to me. An energy block. And whatever you do () whether it’s mental effort or physical movement () you can't unblock it.’

The block is of course situated in her neck. When I mediated with Whimsy, she stated:

‘W: I didn't have time to get where I would normally be but what was really interesting was that having just said () having made a big thing about this out of body experience () you know having a kind of direct line to it if you like. I actually had what I think of as the bog standard experience of feeling my body. Not weighted. Because that's very very unusual for me.

J: So you felt the body () lighter you mean?

W: No I usually feel that I'm unaware that I'm supported by anything. So if you like I don't feel supported by the ground. [...] And I don't usually have those experiences but this time I actually was aware of it.

J: That you were supported?

W: Yeh!

J: And how does that feel is that () positive or negative?

W: It’s positive in a kind of boring way. And so () that’s normal experience! You know: there is a body () you are in it () and it’s on the ground. And that’s such an unusual experience. I spend a lot of time in the kitchen particularly. Practicing this thing of being aware that my feet are on the ground. And that there is a whole planet underneath supporting.

J: Because normally () you feel a little bit () ungrounded do you mean?

W: Most of the time.’

This extract illustrates how I appeared as an actant in Whimsy’s network that at that time had a clear mediating effect on her experience of ME. However, it is conceptually interesting because the implication is again that Whimsy usually feels disconnected from her body. Moreover, she does not feel supported or connected to the physical environment and this further enhances my argument that the relation to the environment is an important feature of ME. However, on this occasion Whimsy did feel what she describes as the mundane, normal connection between body and ground. I pondered my role in this as an actant as part of a network but came to no simple conclusion.

Whimsy’s neck has mobilised around it actants of various types that become implicated in her social relations, or strictly speaking, romantic relations but following the chains of association and connecting up local networks leads to the broader understanding of Whimsy’s ME and its relation to the environment and practices.

It is impossible to know what Whimsy's traumatic event involved. It thus has to be treated as an actant by its absence. In terms of the traumatic event and her father, because they appear in the data as absences, I did not make assumptions about their nature. Instead, I scrutinised what was said around these absences and studied the metaphorical context around them in her talk. If Whimsy's relational difficulties are entangled with ME, there is a risk that a less than critical stance would attribute ME to what happened to Whimsy as an infant. Exploring through metaphor and metonymy the way that material and non-material actants associate and by assigning all actants as ontologically equal overcomes this risk because it avoids calling on abstract concepts as an explanation of ME, for instance by decontextualising 'energy' and using it in an objective way to describe ME.

What Whimsy *has* said about the traumatic childhood event is that it connects OBE, is intellectually in her past but affectively felt in the present and that she uses meditation, breathing exercise and yoga to help keep it out of her house and affectively in the past. There is an association between the traumatic event and breathing and meditation as she uses it to restore the flow of energy through her body and to offset her neck problem.

To draw the discussion together, Whimsy struggles to overcome and has adopted and developed a specific ideology and approach [Buddhist informed meditation] to combat her ME which crystallises around her neck and low energy. She is explicit that this approach also keeps the 'traumatic event' in the past. Her flat is metonymical of her body and her alienation from her flat reprises her alienation from herself. She fears dying in her flat alone and this is associated with her breathing and with city pollution, both metaphorical and connected to death.

Whimsy uses meditation to connect herself to the ground and to feel grounded and this associates with ongoing out of body experiences which are metaphorical of escaping herself and hence the traumatic event. She fears breaking her neck if she becomes romantically inclined to someone. Her neck impedes energy flow. As a child she appears to have had an absence of a loving figure, she had an unreliable mother and Whimsy was not sure whether she was royalty or not. Her father remains an absence. Michel alone has validated Whimsy and unfortunately he died. Whimsy does not believe her ME is going to get better. This assemblage of actants, events, beliefs,

people real and imagined, body parts and so on *is* ME and transcends the boundaries of inner/outer, self/other and mind/body.

7.8 Chapter summary and conclusion

In this chapter I have focussed on the question *how can metaphor and metonymy be used to explore relations between actants?* I therefore used metaphor and metonymy to explore Whimsy's experience and understanding of ME and began by describing what I termed the 'collapse' and which represents for Whimsy the immediate antecedent to her ME. The collapse comprised several associated actants such as her undisclosed childhood traumatic experience, a car crash and an ectopic pregnancy. ME revealed itself via these actants that appeared unconnected but which were interpreted as metaphorically and metonymically associated. Using the notion of metaphor to examine data provided a means of connecting the moves that Whimsy made through her narrative. Whilst Whimsy had made a conscious association between these events, I suggested that via a series of metonymic equivalents, death had become associated with her neck and that her neck had become the focal point and embodiment of her ME. Whimsy's neck was also associated with how she talked about and experienced 'energy'. The issue of energy in ME is important because it is a common feature of sufferer's experiences and psychiatric and biomedical concerns with characterising and managing ME. I described how Whimsy deploys a particular understanding of energy that involves mechanical metaphors of the body and bodily processes. ME is equated with an energy flow that is blocked by her neck.

All the sufferers I worked with discussed the impact of ME on their energy levels with energy deployed as purely physiological, psychological or a conflation of both. However, Whimsy's idiosyncratic use of 'energy' means that attempting an objective, standardised measure of energy is unhelpful. This is significant given that a diagnostic feature for ME is fatigue of more than six months duration. Thus, claims for objective measures of energy, such as Lerner, Safedin and Fitzgerald's (2008) 'energy index' designed to measure the degree of disability in ME patients are non-sequitur because of the inherent subjectivity of the linguistic terms they use to build their scale around.

I proposed the notion of *debilitating space* as a way of framing an environment that associates with different actants such as emotion, energy, pain and the body to effect a negative outcome. My focus was on the manner in which Whimsy associates her flat with feeling trapped, dying and the depleted energy that her neck appears to translate.

Hence, understanding Whimsy's ME necessarily entails exploring the relationship between it and the environment of her flat. The notion of a debilitating space is a useful way of framing how metaphoric processes transcend and connect what would otherwise be understood as dualisms such as inner/outer, social/individual and material/immaterial. A debilitating space is thus representative of my psychosocial framework and is also useful because it contrasts work that has investigated the restorative, enabling functions of spaces and places.

I described how Whimsy described her neck as a site of vulnerability for her in terms of 'romantic' relations. My discussion of this association highlighted the relation between Whimsy's understanding of ME and how it affects her real social relationships. This section brought into focus the manner in which real others become imagined and provided an alternative way of following the links from ME to its social effects.

Finally, I drew together my discussion of central actants and their metaphoric and metonymic relations so as to provide the reader with a sense of the assemblage of disparate and seemingly disconnected actants that Whimsy's ME appears to be comprised of.

Chapter 8

Les: imagining the body in ME

8.1 Chapter overview

In chapter seven I exemplified how I used metaphor and metonymy in conjunction with the ANT framework to explore the associations between actants in Whimsy's experience of ME. The present chapter builds on chapter 7 by addressing the research question *can ANT and metaphor be used to rethink how the body is theorised in ME?* My aim here is to explore the relationality of the body in ME, through a focus on Les, who was selected because of the unusual onset of his ME and the manner in which it implicated a specific body-part and event. Les illustrates the importance of drawing comparisons and contrasts between different ME sufferers in ways that point to the particular yet superficially similar aspects of the condition. For instance, a central discussion in the present chapter concerns how Les's ME is entangled with his heart and visiting a specific place, namely a cemetery. My analysis details how this entanglement may work towards managing the anxiety associated with Les's ME-onset and ongoing fear of relapse. This analysis not only highlights a further specific experience with ME but also paves the way for a discussion of how the body in ME can be re-imagined in terms of its relationality. But I also draw an important contrast in how death and fear are implicated in Les's ME in ways that are qualitatively different from how death and fear appeared to be implicated for Whimsy. The salient feature of the first section is that an event that implies the body can be explored in terms of how that event becomes translated into a feature of ME experience in a displaced manner and as part of a specific material space, a cemetery, which Les regularly visits for 'fresh air and exercise'. In conjunction with this I describe how Les conflates ME with the vagaries of aging and changing bodily capacities. The manner in which Les experiences ME appears associated with how he perceives his self as capable of achieving in the sporting arena and in this demonstrates how ME is highly entangled with an ongoing sense of self and the aging body. Following this discussion, I outline how ME research has had a tendency to present an 'ME body' as an homogenous body, which overlooks the variable ways that parts of the body are implicated in ME. I therefore use Les's experience with his heart and onset of ME with chest pains to draw attention to how ME is often felt in or implicates various parts of the body in different

ways. The penultimate section of this chapter contextualises my analysis concerning the body by outlining the relationship between the body, materiality and discourse. I emphasise that a psychosocial approach can be used to explore the notion that unconscious processes imbue the relationships between the disparate actants that constitute ME. Most important is the notion that a psychosocial conceptualisation of space accounts for the ways in which biomedically and hence politically motivated discourse is engaged with and embodied in particular ways. Finally I explore a view of the body as a dynamic process that is brought into being, rather than as an incarnate entity that unfolds in the world.

8.2 Les's background and central actants

Les is 65 years old. His father was an agricultural labourer and his mother was a home maker. The family lived in a small village and moved into town when Les was around 15. When Les married he moved into a house in the next street and has been there with his wife ever since. At age 11 Les contracted meningitis, although he does not know if it was viral or bacterial. He was treated for this with what at the time was a 'novel medicine' and this seemed effective. Les does not link this event to ME. Les has 'always' suffered with headaches and is unable to be in the sun.

Les received little guidance from his parents regarding life choices and does not report any formal education beyond age 15, at which time he left school to work in a factory. He eventually gave up this work due to the noise and the headaches it caused. He then worked in a nursery and as a labourer for the local saw mill; remaining in the latter line of work until the onset of ME in 2007. Les is now officially retired and receives an 'adequate' pension, stating that he and Dora, his wife, are financially secure.

Les has an older sister [+ 6 years] and brother [+ 2 years]. He has always been close to his brother but less so his sister. Consequently Les does not see his sister that often but his brother visits him 'most Wednesdays'. His brother still lives in the same street the family moved to when Les was 15.

Les has been married to Dora since 1970. Dora was raised and lived in the street next to where they currently live. Les's house is very well presented and feels quite modern. His garden at the time of first visit was in full bloom. Behind his house is a large cemetery and the general area is relatively quiet. Les has seen neighbours 'come and

go’ but does not appear unduly bothered by this, nor by the general growth and redevelopment of the town.

Les has a daughter and a son. His daughter lives in the same town as Les and regularly brings Les’s two young grand-daughters to see him. He is very close to these girls and babysits and collects them from school on Fridays. However, Les is somewhat estranged from his son, who lives in a nearby town. Les initially attributes this estrangement to the influence of his daughter in law and consequently regrets not seeing his 18 month old grandson that often.

Les discusses the onset of ME as chest pains that occurred one Sunday night in 2007. These pains lasted six months before switching abruptly to headaches. Les does not reference viruses at that time beyond a ‘mild cold’ occurring a couple of weeks before the chest pains.

I now describe central actants from Les’s data.

The first actant is **heart-stopping**. One night in 1991, and for no apparent reason, Les’s heart stopped. He now has an on-demand pacemaker. Les does not establish causality between his heart-stopping and ME-onset but intimates that around the time of ME-onset he was feeling overworked with his job and unsupported by management.

Fear of relapse is an actant that crops up explicitly several times across the data and is associated with Les’s day to day experience. It is an ongoing source of anxiety for Les, who worries about relapse ‘pretty much all the time’. Relapse characteristically occurs when Les is out; he comes over ‘faint and giddy’ when he ‘uses [his] strength’, although it is ‘not a lack of strength’. Les avoids some activities if he particularly feels a relapse may occur and is more likely to go out if Dora is with him. On one occasion he states that a relapse would not have occurred if he had not ‘gone out’.

The **cemetery** behind Les's house is an actant.



The cemetery is large, landscaped, has sweeping views of the town and holds 3000-plus graves. Les house spends 20-30 minutes walking around it two or three times each week and does this for 'exercise and fresh air'.

Sport, which I describe as an actant, has always been important for Les in terms of participation and watching. He 'love[s]' sport but ME has had an effect on this in two ways. Low energy means he is less able to participate, although he has recently resumed putting and skittles on a weekly basis as his energy levels have improved. Secondly, fear of relapse prevents him committing to some activities such as attending his local football team's matches. Sport has always been significant for Les in terms of self-understanding. His sense of self is tied up with his ability to perform sport and perform well and this means that ME has had a negative effect on his sense of self.

In the subsequent section I describe the onset of ME for Les and how this might associate with actants such as the cemetery and implicate the body. Of significance is the actant ‘fear of relapse’. My analysis focuses on the associations between this actant and events prior to Les’s ME.

8.3 The body in ME

In the following extract Les has responded to the question ‘tell me about your ME’ and begins in terms of ME-onset. Les states:

‘L: What when I first had it? Umm. Sort of fe- felt a funny pain () sort of ache or what was it in my side () here. I thought () oh () and went to bed it woke me up feeling funny so my wife called the ambulance [inaudible] said it was chest pains () and they whipped me off to hospital. They were looking at me and I thought () well () they give me some morphine eventually but that didn’t clear it. () So they still didn’t know what to do with me. I got heart problems anyway so they thought it was down to heart. So ahh...

J: When you say heart problems () what...

L: It stopped!

J: It stopped?

L: It stopped! (laughs) one Friday night in 1991 it stopped.’

Onset of ME with acute chest pain as the only symptom is uncommon. Les begins the extract by describing chest pain before introducing his ‘heart problems’. The shift from ME-onset to ‘heart problems’ does not strike me as problematic because the latter logically follows as an explanation of how doctors responded to him at that time. However, the transcript reveals that our subsequent discussion is about his heart and not ME and it is some time before Les returns to ME, explaining that after six months the original chest pain abruptly switched to a headache:

‘L: Yeh it’s all different now [inaudible] well mainly it’s headaches at the moment. Fuzziness () I say last Saturday I had a ma- a little bit of a relapse. Came over bad in town. The first time I had that for about eighteen months.

J: When you say relapse what what happened () do you mean?

L: I felt () shaky and [*slumps forward, mimics the physical symptom*] could hardly hold myself up. So my wife got a taxi and we got home. [inaudible] eased off it didn’t last. When it’s happened before it’s lasted quite a while and it’s a lot worse.’

In this second extract the shift in narrative from headaches to fear of relapse is significant because the latter does not obviously follow and this suggests an affective

movement has occurred for Les. The next extract is the opening of our second meeting and illustrates me following-the-actor:

J: Yeh so () let me see. Yeh I got () three questions actually. The first one is how often do you find yourself worrying about a relapse?

L: I would think () pretty much all the time really. Cos I hope I'm not gonna have one when I go out. And when I had that little one that was the first time it happened () when I went out.

J: Had you been worrying about relapsing up to that point?

L: Not really it's just a general it's sort of in the back of your mind all the time really I think. But I hadn't had one for about eighteen months. That was the last of them. But it wasn't as big as the other ones. Cos the others ones she's had to call the ambulance () out. And it was the last time they didn't take me to hospital but normally they would take me to hospital. I said I don't want to go up there! It'll be four or five hours mucking about and they'll just say go away at the end of it ha ha!

J: Did you get any particular chest pains with relapse?

L: No. Relapse is feeling really () the whole body just goes into break down. I feel weak and wobbly and have to sit down. Or flop out and () wait for it to go away'.

My first observation is that it is the fear of relapse that affects Les's ability to go out and not ME *per se*. Les's last statement is particularly significant because relapse is expressed in terms of a definite state or a limited set of events. As noted above, fear of relapse associates a lot of anxiety for Les and can be thought of as an actant that has effected a problematic state, co-opting other actants into association with it.

Of equal significance is the metaphor of the body entering breakdown. This is the only occasion across the data set where Les explicitly discusses the body apart from one other instance where he explains how the initial pain shifted from his body to headaches. Les objectifies his body by referring to it in the impersonal tense, reflecting how female ME sufferers talk about and objectify 'the whole body' (Hart and Grace, 2000). Yet *he* ['I'] feels weak and wobbly, implying that Les might experience his body as differentiated from his sense of self. His body 'goes into breakdown' is metaphorical of a mechanical object failing and Les's heart failed him in 1991. There is thus a metonymic translation between this event and failure of the body in general in that the anxiety associated with Les's heart-stopping appears to associate with the onset of ME. Chest pain in the latter is metonymically equivalent with the failure of his heart in 1991. ME-onset can be thought about as a past traumatic event that has been temporally displaced. At least two things point in this direction.

Firstly, the nature of his heart-stopping and the ME-onset is similar, as is the manner in which Les narrates them. In both cases there is ambiguity in terms of what occurred. ME appeared as a ‘funny pain’. When his heart stopped he states he ‘was feeling ever so funny.’ The use of the word ‘funny’ may be coincidental. However, he uses the term ‘funny’ on three other occasions; once more during our first visit and twice in the third. On each occasion the word is used to describe how he was feeling during relapses. The term ‘funny’ is significant and has become metaphorically related to, and hence associates his heart-stopping, ME-onset and relapses. In chapter four I discussed ‘switch’ words. Freud (1905; p.5) refers to these as a word or phrase which often appears in an individual’s narrative. The switch word serves as a nodal point on which various unconscious and conscious thoughts converge. The switch-word ‘reveals and conceals’ the meaning of a symptom (Litowitz, 2013; p.2). It is useful to think about Les’s use of funny in this light as it may suggest a metaphorical association between Les’s conscious understanding of events and unconscious anxiety.

My interpretation that ME-onset associates with Les’s heart-stopping is that they both occurred in the body and were experienced in the body. In relation to what caused his heart-stopping he states:

‘L: They don't know. () They () did all tests and all that they didn't know’.

In relation to ME-onset he states:

‘L: And they done all the tests. They still didn't say what's was wrong with me so they sent me home again.’

Both occurrences are figuratively *and* metonymically similar. Moreover, there may also be an association with Les feeling funny, in that the physicians’ inability to know what was wrong with Les metonymically reprises his own vagueness about what occurred at ME-onset. Thus, Les appears to understand both his heart-stopping and ME-onset in the same affective and cognitive modes. Fear of relapse is one factor that might be restricting Les’s behaviour, more significantly perhaps than the effect of low energy. But perhaps the latent anxiety concerns his heart.

Finally, I note that when Les described what a relapse feels like in the extract above he mimics the general slump of the body that he also enacted when his heart stopped in 1991:

‘L: I was feeling ever so funny. And then my wife said she’d get a cold compress for my face and I slipped down on the floor.’

My interpretation is a metonymic association between fear of relapse and his heart stopping in that they involve a similar affective state that became embodied in a similar manner.

The salient feature of this section is how an event that implies the body directly might become translated into a feature of ME experience in a displaced manner. Moreover, my analysis illustrated how metaphor can be used to trace associations between different domains, such as the body and Les’s cognitive understanding of ME. In this regard the analysis illustrates the importance of identifying cross-domain translations as well as the need to scrutinise data for instances of metaphor that appear in different linguistic contexts, such as ‘funny’. However, in this section I have not addressed the significance of the body in terms of its heterogeneity. I have focussed on the heart but this was used to represent Les’s general bodily relation to ME. In contrast it is important to recognise that ME affects the body in terms of its parts as well as a whole and that sufferers’ narratives, such as Les’s will, reflect shifts between these two aspects. Whilst focussing on the whole body may provide an overview of how ME is experienced, focussing on specific, heterogenous body-parts provides a nuanced view of how ME is associated with and affects parts of the body in different ways.

8.4 The cemetery: the translation of a bodily event

In this section I describe how the relationship with the body may be translated into specific behaviours. I use metaphor and metonymy to suggest why the cemetery is significant for Les and how it connects to ME and Les’s body.

As I went through the transcription process and initial thematic analysis I felt Les was trying to tell me something whilst we were in the cemetery that he could not articulate. I could not imagine what this was but added to my notes to stay with this feeling and see what emerged. During the tour of the cemetery [3rd visit], the majority of what Les pointed out to discuss with me concerned grave stones and the state of the cemetery and was about damage, restoration and acknowledgement. ‘Tramps’ frequented the cemetery and had left a bag of clothes. Badgers had dug up the graves and scattered bones. The following two photographs are of a badger set Les stopped to show me:



‘Vandals’ [‘kids’] used the cemetery to ‘do drugs’ and damage the gravestones. He also pointed out specific headstones. For example one of a soldier killed in the Second Boer War, which Les went out of his way to show me:



I did not appreciate its significance at the time but during my third visit Les says the following:

‘L: That's why yesterday afternoon I felt (1.0) all sort of () all () don't know () I thought I'll go for a little walk see if that does anything and it did () it done the trick. (3.0) // Cos ah () the cemetery is full actually.

J: The cemetery is full?

L: Behind us is full. So you can't have new () um () burials there. I looked in and it looked like a new grave was there. But that must have been a plot that was a family plot.

J: Oh I see!

L: So I went and had a look and it was August () 26th he died.’

In first line of the extract, Les suddenly switches topic [indicated as //]. He had been talking about low energy and relapses. Sudden shifts in narrative are one way of noticing a metaphorical or metonymical translation becoming activated. Metaphorically, if the cemetery is full then no-one else, including Les, can be buried.

Les visits the cemetery for a walk two or three times a week. So what are cemeteries about? Rationally, Les explains it as ‘exercise and fresh air’. Metaphorically, of significance is the manner in which Les brought to my attention that headstones [to remember the dead] become damaged [which means we cannot remember the dead] and thus something had to happen for the damage to be repaired and the dead remembered again. If these observations arose from one session I would be less inclined to think about them actantially and this speaks of the need to follow-the-actor and lines of association in an exhaustive manner, before making explicit associations. However, instances in this vein do appear in three separate sessions explicitly.

In transcript one Les described a trip to America and how he visited Gracelands, where Elvis is buried:

‘Well it's strange really it's like going back in a time warp. Cos everything stopped still to when he died [...] and he's actually been moved () he's buried there now. With his brother () mother () and father and twin he had a twin who died at birth. So ah () he's got them and you got a little church thing as well. It's it's sort of () well! Ha ha. Strange feeling!’

I am particularly intrigued by how he talks about Elvis in the present tense as having ‘got them’, which may suggest a temporal translation where Elvis is somehow still present and perhaps this means that Les unconsciously experiences issues around death and being dead in a complex, atemporal manner.

Elsewhere, Les is explaining the construction of a cemetery in New Orleans:

‘L: And if something’s gonna happen they all should get out and they shut the gates. Cos they used to have bodies floating about cos it’d flood. So they got all the concrete things they put em in.

J: Oh crikey to keep em in place?

L: Yeh. But that didn’t work when that hurricane happened. Even that failed.’

In other words, damage could not be prevented. Further instances pertaining to damage and the cemetery are the badgers, which have undermined graves and thrown up human bones. Les stopped to show me a badger set and discussed their damage in these extracts:

‘L: All this grass () when the um (1.0) badgers were out () they dug it all up! You’d think a (1.0)

J: Bulldozer?

L: Or thing that churns the ground up.

J: Oh rotavator!’

And:

‘It’s unbelievable when someone said the badgers had been doing it cos they actually found some bones lying about. They’d been underneath just digging up bones. So the crematorium had to come out and take em to the crem and burn them.’

Les appears incredulous that the badgers could intrude on the cemetery. Vandals and kids have also damaged the cemetery. One or two graves have been restored, but Les can’t understand why:

L: If we go up this way there’s um () a grave up here they restored. For some reason [...] I’m surprised it hasn’t been damaged again.

J: Was it damaged and they restored it?

L: Yeh well it’s probably been damaged for a long long time. Why () they picked up and done that I really don’t know. That don’t make a lot of sense to me.

The damage that occurs in the cemetery and in New Orleans intrigues Les because it seems unreasonable to him and cannot be prevented. So the cemetery, primarily his cemetery, is a space that potentiates something beyond just walking and taking air.

Exploring damage and the cemetery metaphorically and metonymically opens up possibilities for thinking about Les’s experience of ME. Firstly, at no time did Les mention death or dying to me explicitly, not even in terms of his heart-stopping. Does

this mean that the cemetery and talk of damage and restoration is a displacement of this?

I thought about death in relation to Les as the ultimate destruction of the body. This associates with Les's onset of ME and the feeling of a chest pain because I interpret them as a translation of the original heart-stopping incident some years before. For instance, Les visits the cemetery which is a sight of conflict between death and damage and restoration. The materiality of the cemetery is involved with the mediation of his affective response as part of ME and ME clearly implicates Les's body.

Thinking about this relation between embodiment, materiality and affect challenges the liberal notion of the self contained individual (Mulcahy, 2012) and I apply this challenge to Les and his ME because it implies less than transparent relations between people and things. The absence of explicit references to death and Les's heart-stopping are perhaps metaphorically translated into the cemetery, where death is represented as an absence; the thing that Les cannot consciously tolerate. The 'damage' which appears to concern Les can be rethought as a metonymical translation of the damaged heart. The heart is itself associated with the original chest pains which as discussed mirror the onset of his ME. The fact that Les comes into the cemetery on a regular basis is important, as are his discussions about it, and brings to mind the *return of the repressed* (Freud, 1900). The return of the repressed is the process whereby elements that have been repressed or locked away in the unconscious reappear in consciousness or in behavior. However, this return occurs in a form that is not recognisable and is instead apparently disconnected. Freud (1933; p.74) states:

"...impressions [...] which have been sunk into the id by repression are virtually immortal; after the passage of decades they behave as though they had just occurred."

This idea is important because it frames the temporally transcendent nature of events and brings to mind the manner in which Les returns to the cemetery. For Les, the terror that may be associated with the experience of his heart stopping and having a pacemaker may continue to exist in an ongoing yet displaced form. Les's narration and use of the cemetery points in this direction. Every time Les enters the cemetery he unconsciously re-experiences his heart stopping and this is an alternative to the rational explanation that Les manages his ME by going there for air and exercise. But going to a place where the terror of death is re-experienced albeit unconsciously appears

counter intuitive. However, Les's recourse to the cemetery reflects complex conscious and unconscious processes.

Les's relationship to the cemetery also brings to mind the notions of *transitional objects* and *phenomena* as discussed in chapter three. These terms describe a range of objects and experiences that are involved in the infant moving from "relating based in internal, subjective experience toward awareness and use of an external, objective world of objects" (Cancelmo, 2009). In this sense, the cemetery is involved in Les negotiating his affective world, which may be largely unconscious, and an attempt to translate it into something meaningful, embodied by/in the cemetery and which is materially tangible for him. However, this explanation is limited because it implies an affective experience that pre-exists the cemetery. In contrast, I want to emphasise the co-extensiveness of the cemetery and Les's affective experience with ME as an ongoing arrangement.

The cemetery *can* be thought of as a means of keeping in touch with the unconscious anxiety associated with his heart and ME and his repressed fear of death. But there is also a reciprocal relation between Les's affective world and the materiality of the cemetery because the latter has an autonomy of its own that is beyond Les's control (Pile, 1996). Les has not arrived at the cemetery and utilised it as a stable, extant symbol. In contrast, the cemetery has made itself indispensable to Les on its own terms because of certain potentialities it held, such as damage by badgers and restoration of graves. The cemetery is in a dynamic state of damage and repair and this ongoing movement provides an affect-laden space where Les can negotiate and renegotiate his relation to his heart-stopping and ME also as an ongoing, dynamic event.

At this point it is important to draw a comparison with Whimsy. Whereas Les does not discuss death explicitly, Whimsy does. For Whimsy, certain actions such as being hugged and being in her flat have become associated with death and yet death for Whimsy appears to be structured around vastly different experiences. What I take away from this is that whilst there may be intuited, universal unconscious anxieties about death, the manner in which these anxieties manifest themselves and are managed are vastly different and are clearly mediated by specific places in specific ways.

Hence, exploring ME as situated in specific places and affective spaces, especially ones such as cemeteries, which are already filled with affective intensity, provides a lens on the types of activities ME sufferers might engage in and why, as well as

highlighting the complex interplay between conscious and unconscious processes that may appear to result in counter-intuitive behaviour. In Les's case, approaching his visits to the cemetery in this manner provides an alternative view that complements a rational understanding of activities designed to ameliorate ME such as paced exercise. Les's relation to the cemetery is such that not only can it be explored in terms of rationalised exercise but also has a site that mobilises specific unconscious anxieties concerning death and his heart that are inextricably linked with how he experiences ME.

8.5 Body parts

It is important to highlight the manner in which parts of the body are implicated as well as the body as a whole, to draw attention to the heterogeneity of the experience of the body and hence ME. At times Les's heart and chest are salient. At other times, as discussed, Les's head is the centre of his ME experience with headaches. This is in contrast to what I suggest is the totalising tendency of research (i.e. Moss & Dyck, 1999; Soderlund & Malterud, 2005) to represent an homogenous 'ME body'. The ME sufferers I worked with moved between parts of their body and representation of it as a whole and this implies that the sufferer is experiencing their body at different times in different ways.

By focussing on body parts rather than abstract whole bodies I got closer to understanding the particular experiences of ME. The ANT/metaphor framework highlights each body as itself an heterogenous assemblage of various actants that function in association with other parts and other actants beyond the body. For instance, Les's heart is not understood in a rational, direct causal relation with his ME. Instead, the heart as a physical entity in the body is displaced from site to site as described.

However, I have not considered the role that Les's pacemaker plays and this provides a direct, material mediation of his heart. Suffice it to say the pacemaker as an actant can also be thought about in terms of the 'failure' and 'breakdown' metaphors that Les deploys and which associates with his anxiety in a different way. Thinking about the material displacement and mediation of the body could therefore involve tracing associations between, for instance, viruses and particular aspects of bodily function in a fine-grained manner and this further establishes the particularity of ME for each sufferer and helps avoid stereotyping ME sufferers.

In this section I have emphasised that research can present the ‘ME body’ as homogenous and this overlooks that ME experience is often felt in, or implicates, various parts of the body. Focussing on the associations between body parts and other actants and understanding them as an assemblage results in a particular understanding of the heterogeneity of the body in relation to specific individuals and the specific spaces they engage with.

8.6 Rethinking the body in ME

Previous sections in this chapter have described how I explored the associations between Les’s ME experience, specific body parts and the potential anxiety associated with his heart stopping and fear of relapse. These actants may have become entangled with the cemetery in ways that enable Les to work through what amounts to complex conscious and unconscious processes.

In the present section I draw these discussions together to outline how I have thought about the body and its connection to space and place in line with ideas about the need to re-envision the relationality of the body, materiality and discourse. I conclude this section by referring to Latour to think about the body as a dynamic process that is brought into being, rather than as a being that unfolds in the world.

From the perspective of ME, the body has been theorised and discussed in terms of discursive, material, political and social processes and how these are connected (Moss and Dyck, 1999). Moss and Dyck’s review and subsequent study note the general move to bring the body back in to research by building a spatial body politics that accounts for importance of embodiment and the inherent relationality of the body. The implication is that the body is not a site that functions under the autonomy of, or with, the self. Instead, the body and how it is experienced is mediated by social and political discourses which produce various types of identity, reflecting contested notions of normality and disability. Moss and Dyck also cite the work that is being done to “challenge the dichotomy of discourse and materiality” (*ibid.* p.373) by focussing on the relations between place and body, such that notions of space can be rethought as places where embodied social processes are contested. These processes result in dominant cultural narratives about how people are supposed to behave in given circumstances.

My perspective is that the process of re-imagining the relationality of materiality, discourse and the body has been hindered by the ontological differences between them. Moss and Dyck focus on women's experiences of ME to assist in building a radical body politics in terms of a *corporeal space* where the "discursive and material bodies are experienced simultaneously" (*ibid.* p.389). They draw on and critically evaluate work such as Probyn, (1993), Rose, (1993) and Grosz (1994), that has explored the relations between the body, materiality and discourse and conclude with the need for an approach that reconciles power, body, materiality, discourse and the non-Cartesian subject so that the fluidity and simultaneity of these elements can be maintained. I read Moss and Dyck's work as implicitly rational in that discourses are described as having fairly predictable, causal effects on the female ME sufferers they worked with and Moss and Dyck do not report the idiosyncratic relations between specific individuals, ME and particular spaces. The diagrammatic and structural language used to describe corporeal space belies the difficulty in representing the relationality that Moss & Dyck attempt to convey and perhaps then the central issue concerning the relationality of body is the inadequacy of articulating how it is experienced. As Shilling (2003; p.10) puts it:

"To begin to achieve an adequate analysis of the body we need to regard it as a material, physical and biological phenomenon which is irreducible to immediate social processes or classifications."

One of my concerns has been to emphasise the ways that ME experience is both particular and full of confusing and apparently unrelated or contradictory experiences and objects. Les visiting the cemetery for instance and the manner in which he emphasises damage and restoration does not necessarily reflect the biomedical approach to characterising ME. However, from a psychoanalytically-informed stance, the metaphoric translation between Les's heart, the cemetery and fear of relapse is reasonable and indicates how medical discourse about how to engage with ME as a sufferer becomes personalised.

ME sufferers, as has been the case with Les, are often counselled on exercise moderation and conditioning techniques, such as CBT, pacing and graded exercise therapy to avoid boom and bust energy expenditure and to maintain muscle condition. From the dominant cognitive and biomedical perspectives, the meanings that ME sufferers attach to symptoms and hence their body influence the sufferer's illness behaviour. This premise provides the rationale for CBT. Thus, when sufferers engage

in techniques to aid their ME, they are engaging in activities that are politically and epistemologically motivated.

From a biomedical perspective, Les *is* moderating his ME with exercise by visiting the cemetery regularly and in that sense is addressing his ME in a reasonable manner as a ‘good ME sufferer’ [my emphasis]. This is a rational explanation because it reflects how politically motivated dominant biomedical discourse suggests Les should act. But from another perspective the cemetery is a place that only exists because of death, mortality and bodies. Of all the kinds of exercise and all the kinds of places he could visit, Les visits particularly the cemetery and this suggests aspects of behaviour that are imbued with unconscious processes. It suggests that whilst his experience of self is autonomous there are other factors through which that self experience results that are beyond conscious understanding. The cemetery is therefore a psychosocial space where the politically motivated nature of management-practices is embodied. It is also a space which is co-extensive with Les’s body and the trauma it has suffered and how he manages this trauma both consciously and unconsciously. The body and how it is experienced is thoroughly entangled with a particular material environment to form a psychosocial space specific to an aspect of how Les experiences ME.

In my methods and in my analyses I approached ME indirectly to provide a sense of the way that it is entangled with the body and materiality in less than obvious ways. The relational ontology of ANT decentres the body and re-envisions it as one actant amongst many at the same ontological level. In this sense the body and body-parts take on specific identities reflecting associations with specific material and non-material actants. It is the specific arrangement of actants and associations that potentiate the various identities of the particular body or parts therein, in a particular context. Knowledge of the body, indeed of *one*’s body, is therefore also embedded in embodied practices that cannot necessarily be articulated (Pink, 2011).

I take from Pink the notion of how space is itself unbounded; intimating the dynamic flow of relations that an emplaced body involves. As a body enters a space both physically and relationally, knowledge of and about that body undergoes a dynamic transfiguration and the body, or rather a specific body, comes into being (Pink, 2011; p.348). What this brought to mind was how Les’s body and hence his ME is transfigured as he enters and engages with the space of the cemetery. As he enters that space, a change occurs where the elements of the cemetery become entangled with

Les's physical body in a specific way that gives rise to his experience of being there and his knowledge of ME at that time. I infer from this the irreducibility of knowing the body or indeed the self because these are always integrated as part of a specific space as an ongoing event or dynamic.

However, as soon as one distinguishes between discourse, materiality and the body then the inevitable outcome is a structural explanation [of ME], such as 'diagnosis confers legitimacy'. Les's relationship with the cemetery is not without conflict and is certainly not transparent but it is the conflict and the irreducibility of his ongoing experience that makes it so meaningful for him due to the associations with death, damage, reparation and restoration, and which are non-representable in terms of standard discourses about the ME body.

Les's heart-stopping is an actant in the material domain that metonymically translates his real heart into the domains of affect and the environment. This is reflected by his avoidance, in narrative, of the damage and trauma associated with his heart and the consequent displacement of that trauma into the cemetery. These translations become understood as, or part of, his ME; which is metonymically translated into the materiality of graves and damaged gravestones by means of negotiating the affective relation to his compromised physical body. In turn, these translate metaphorically as loss of the body and recovery of the body, serving to hold in place the original translations. In other words, through the cemetery Les can maintain contact with his body, particularly his heart and his fear of it failing, whilst at the same time retaining albeit metaphorically the wish that it will be repaired and restored.

All of the translations involving Les and his heart are coextensive in that they exist across time and place and the various domains that each of them represent. They are dynamic in the sense that there is constant movement between the actants involved and the space that the cemetery forms. Les's body can be thought of as a thing in itself only because a boundary has been established, by convention, between his body and the rest of the world or between his body and for example a gravestone. But that is because of the way that Western culture tends to make sense of the world via certain categories and metaphors in the first place. Alternatively, my approach highlights how the body in ME is experienced in ways that incorporates the particular embodiment of non-dualistic psychosocial processes.

The cemetery was always behind Les's house, waiting, as it were, for specific potentialities which it held to become associated with Les. In 1991 Les's heart stopped and his bodily perception was radically altered. To make sense of this and to negotiate the anxiety that Les experiences as a displacement into ME and relapse, the cemetery has made itself indispensable in an ANT sense. This is not to say that there was something that could be labelled as anxiety in an objective sense that appeared when Les's heart stopped and which he then translated into ME. Instead, the anxiety is the way that his heart-stopping associated with other actants at that time. Anxiety in this sense is being registered as an effect of certain actants associating and not as a thing in itself.

The cemetery is a space where Les can maintain contact with translated representations of his damaged body [as holes, damaged graves, bones and so on] as well as the phantasy of reparation and regeneration [repaired graves, acknowledgement via headstones, and a full cemetery where his dead body wouldn't fit]. From this perspective, the cemetery represents to Les *his* body and is a psychosocial space that transcends any of the material elements that it is comprised, one of which *is* Les's body.

When Les is in the cemetery, he perceives his body as compromised. But for others, such as his wife Dora, when Les is in the cemetery his body is represented as compromised because that is ostensibly why Les is in the cemetery in the first place. The cemetery is a site where Les's body presents ME in a way that is visible to others; by demonstrating the activity of exercise. In this sense at least his ME is entangled with the politically motivated discourses of how to manage ME, though it cannot be reduced to that reason alone. But Les also visits the cemetery because it is a space that has become affectively habituated as part of Les's ME experience. In other words the notion that the affective, felt experience of ME is comprised of the dynamic yet patterned relationships between people, things and places.

For Les, the cemetery is a space crucial to managing his ME. However, the relationships between Les and the cemetery and indeed between Whimsy and her flat [chapter 7] and John and his flat and the cinema [outlined in chapter 5] are subtly different and suggest that space and peoples' ME-relationships with it are variable. This is why an analysis that accounts for particular relationships is crucial. Whilst John escapes his flat and the anxiety associated with it, Les actively seeks out the cemetery.

Whimsy cannot escape her flat and hence anxiety is ever-present. Leaving anxiety in the cemetery works as a metonym but a more suitable description is that Les regularly goes to the cemetery to work through and reconstruct anxiety as a dynamic process. This is a more suitable description because it connotes how anxiety for Les is established in terms of the associations between specific actants and places and which may involve dynamic changes. However, a different aspect of Les's ME can be presented to the one described thus far and which highlights not only the variable manner in which ME is experienced in certain ways at certain times but also how the notion of thinking about the body as part of specific psychosocial spaces is useful.

In the following extract Les describes how his ME 'goes' when he is putting [golf] with his friends:

J: So you find that when you go out playing your awareness of ME disappears?

L: It's gone!

J: It's just gone completely?

L: Concentrating on my playing.

J: And do you find you () in terms of managing behaviour () you think: oh no! I've overdone it?

L: No. There's one or two times I didn't play when I got up there.'

What this implies is that ME is not so overwhelming that it is a constant presence in Les's ongoing experience and as an object it moves from foreground to background (Paterson, 2001). Les's ME appears transient and related to activity, context and hence certain spaces. He reiterates this on another occasion, this time when playing skittles:

L: Yeh. Missed a few games of the skittles cos I got there and I just didn't feel () I could play. The last time I played after the first one I was all shaky.

J: Oh right. Cos you were just tired or fatigued?

L: Or I was excited cos I got a good score ha ha ha!

J: Oh right.

L: It wasn't that we were playing really awful!

J: So it wasn't necessarily the energy? It could have been the adrenalin maybe?

L: It could have been. Cos ah () I been playing badly really badly since I gone back. First couple of games I played well and since then it's just gone phwapp! Ha ha ha ha I was hoping to get back () it's a little bit better at the moment. I've played three times. Not that good scores but () good enough.'

Les provides an alternative for his shakiness that does not imply ME and Les's sense of self is very much tied up with his ability to perform and perform well at sport,

which means that in a conventional sense ME has had a deleterious effect on his self. Yet, in the preceding extracts Les sidelines the opportunity to establish ME with fatigue and hence as fatigue affecting his performance. Instead, he flags up an aspect of how he understands self as comprising his ability to perform at sport:

J: Does it bother you if you don't get good scores particularly?

L: Well I'm not happy about it cos I'm a winner. I hate losing. Ha ha ha I hate losing! I always have done.

J: So when you say you're a winner then is it during the game itself that you kind of feel that?

L: Well () I'm () come on I wanna win! [*Les gesticulates with his fists*] I wanna win I've always been competitive in all the years () football and cricket and anything I play I got to win.

It is clear that Les's sense of self is related to sport and performing and that during such times as he is playing, a certain affective response is felt in his body that was reprised in our discussion. The implication is that particular activities associate with particular relationships with ME and the body for Les. When Les is playing skittles or golf, his body is able to perform well enough and this is associated with a positive view of self. Les's knowledge of his ME at these times is likely different from when he is in the cemetery, where ME reflects different dynamic associations.

It is therefore useful thinking about the spaces inscribed by golf and skittles from the metaphorical and metonymical perceptive. Whereas the cemetery is imbued with death, damage and so on, the putting green or skittle-alley appears not to be and anxiety is not present for Les. ME and the body are experienced in different ways that reflect how Les's body and his understanding of it results from the transformation that occur as the body physically enters and becomes part of different psychosocial spaces comprised of different associations.

A further aspect of Les's ME that directly involves the body is how the aging body is understood.

Les ties ME and its effect on self with what may or may not be normal aging. He is ambiguous concerning his declining energy and ability to perform and is unsure whether this is primarily ME or age related. For instance, he explains part of the reason for giving up football at age 32 as:

L: Well yeh and I was getting slower () in my thirties. I had to move back in defence cos it's easier in defence than up front! Too slow () to score goals ha ha.

In other words a clear, age related effect. This was before ME appeared. But in another visit, again discussing playing football, he utilises ME in a more standard way:

J: Have you found you think you've slowed down as you age or is it mainly the ME?

L: I would think it was mainly the ME. Cos I used to keep myself fit and go for runs. I got a treadmill upstairs .

J: This is because of the () to keep your heart fit?

L: No just general fitness. I was playing football and all that and I thought well I'm gonna keep going cos when you get older you slow down really quick () quicker. I was () determined to keep myself fit. But I can't do that anymore.

J: That's just cos of the ME?

L: Just cos of the ME yeh.

Here, in his initial reply, Les establishes a position where ME is prioritised but he also mitigates against scepticism that age is involved. He then acknowledges that aging has an effect before firmly establishing ME as the cause. However, this extract does not fit with the explanation above.

There is also a conflation of age and how Les responds to his ME. Les explained to me in the last meeting that he has accepted his ME won't get any better. In the following extract he links this to age:

L: Yeh cos if I was younger I just wouldn't accept it. But I don't think there's any use fighting it cos it'll just make you worse.

There is a clear implication that age has deleterious effects which means not only can he not perform but he is less capable of improving his ME. On the other hand, he is fully aware that people do recover from ME:

L: And there's quite a few people who said it just went like that. Well I find that hard to believe. Well Michael Crawford. You know Michael Crawford?

J: Yeh.

L: Well he had it apparently. And he's back in the West End now

One interpretation is that Les is validating the seriousness of ME by doubting it can be recovered from and by emphasising that he won't recover. Overall, whether or not a sufferer utilises standard discourses to explain their ME, such as 'it is a virus' or 'I

over did it', depends on the saliency of the context of talk and activity being undertaken. In this case, Les's sense of self and love of sport was most salient on some occasions whereas on others less so. Age appears to be conflated with ME in terms of the ability to recover from it. This highlights the benefit of thinking about the metaphorical and metonymic aspects of talk in terms of exploring the linguistic context for the ways that metaphors are complexed and how they are deployed to narrate specific topics or experiences. For instance, one aspect of metaphorical interpretation is that his age means he cannot put up a good fight against ME.

But of course, the physical body does age and in Les's case there is a translation between a young body and an older body that he has to account for. In this sense, the body's ability to perform is entangled with discursive use of terms such as ME and overwork as well as specific physiological changes. His initial reason for quitting football ties in with his failing ability to perform and hence his sense of self being affected. Later, ME is prioritised and this is used to rationalise stopping football. However, using the ANT notion of translation frames an exploration of the unconscious labour that Les might have to carry out to reconcile his aging body with an impaired sense of self that needs to perform visibly through sport and the anxiety that this may cause.

In this section I have focussed on how Les's body can be explored in terms of a dynamic relation with space and place in line with ideas about the need to re-envision the relationality of the body, materiality and discourse. This is important because bodies represent sites where social processes become embodied and contested. However, the body and its relations are irreducible to these social processes or linguistic classification. To try to capture this irreducibility and also the particularity of ME I described how Les's body and his knowledge of his ME comes into being as he engages with the space of the cemetery. Various actants such as graves and damage and his failed heart become entangled with Les's body in a specific way that gives rise to his experience of being there and his knowledge of ME at that time. Thinking about the body in this way reveals the manner in which discourses about ME, such as the need to exercise, motivate Les's behaviour in that whilst in the cemetery his body demonstrates or performs ME for others and for himself. I also outlined how ME and its relation to Les's body is mediated in different ways in different spaces that reflect

not only Les's experience of ME and self but also how ME is reconciled with his body as it ages.

8.7 Final thoughts on the body

Interrogating what a body is and how it relates to space and place is a useful way of exploring ME. Latour (2004) reframes the question of what a body is by rethinking the body not in terms of the residence of a super-ordinate entity such as a soul, nor in terms of the 'matter' of science that is made of primary qualities in a physical sense. He also points out that even a phenomenological subjectivity is a myth that is attained by ignoring or discounting all the extra-somatic material resources that are in fact used to register experience and through which the body learns what it is. Instead of asking what a body is Latour reframes the question in terms of what allows the body to be registered in the first place, arguing that the body is:

“An interface that becomes more and more describable as it learns to be affected by more and more elements.” (ibid. p.206).

In other words, the body is only part of a dynamic trajectory by which people learn to register and experience the material world and perhaps Latour's sentiment is also useful in turning the gaze outwards from the body to its relations.

When Les is aware of his chest pain and fear of relapse or when he had original chest pain in 1991 and his heart stopped, he was becoming aware of a relation between him and the world and his body. This view can be turned outwards such that when Les's heart stopped in 1991 it brought into association things such as a pacemaker, doctors, procedures, a different self understanding, and an altered social persona. From this view, Les's body can be explored in terms of the associations that constitute it and those it constitutes, rather than as a site where the effects of external events are registered.

What I take from Latour's argument is that the body, or rather a certain body or body-part, has to be brought into being. Of course, Les's heart existed as a material fact before 1991 but since that time it has become part of an actor network in a different sense. Les is aware of his heart as part of a dynamic arrangement of other actants, such as a pacemaker. Les's heart, like all hearts, had a potentiality that it could stop at any time. In 1991 that potentiality become associated with other actants that remain[ed]

hidden from view and yet became realised. A new identity came into being. As Latour (2004; p.207) notes:

“Acquiring a body is thus a progressive enterprise that produces at once a sensory medium and a sensitive world.”

The process of acquiring a body is the means of effecting the world and being effected by it.

Against this backdrop, Les’s body as effected by his heart-stopping, and now by ME, necessarily involves actants such as his pacemaker and the cemetery because these are the extra-somatic actants with which the whole experience is registered for Les. The cemetery as part of Les’s ongoing experience of his body with ME is indispensable, as is his pacemaker. Of course, in the ANT spirit, it can be argued that the pacemaker has made itself more indispensable in its translation of other actants than the cemetery. But I would argue that this is the view from the type of perspective I am eschewing in the first place. With Les, his ME body, or parts of it, had to be produced. His heart-stopping meant that a certain relationship to the body was acquired that then became structured as part of the material space of the cemetery and hence ME.

8.8 Chapter summary and conclusion

The central element of this chapter has been a reconsideration of the body in ME. I addressed the question *can ANT and metaphor be used to rethink how the body is theorised in ME?* To this end I discussed the onset of Les’s ME and the incident of his heart-stopping and outlined how I associate these with his habit of walking round his local cemetery. Exploring damage and the cemetery metaphorically and metonymically opened up different ways of thinking about Les’s experience of ME. Associating actants in this way enabled me to think about how the body might become translated into features of ME experience that imply things and places that are not considered in standard approaches to ME. Conceptualising the relationality of the physical body in terms of other actants and displacements challenges the notion of a self-contained unitary experience of ME and the anxiety it entails.

I drew attention to the heterogeneity of the body and contrasted this with existing tendencies to treat it as an homogenous whole. I discussed aspects of Les’s bodily experience, such as the heart, chest pains, fear of relapse, and his head and how these

constellate as part of his ME. Focussing on body parts rather than abstract whole bodies brought me closer to understanding the particular experiences of ME.

Bringing material spaces into ME, especially ones such as cemeteries which are filled with affect, and exploring them through the psychoanalytically inclined lens of metaphor and metonymy provides alternative insights into the relationships between ME, the body and the types of activities ME sufferers might engage in. From one perspective Les is moderating his ME with exercise by visiting the cemetery regularly. From a different perspective, thinking about why Les visits the cemetery particularly opens up a way of exploring behaviour that appears imbued with unconscious processes and anxiety.

I outlined how Les experiences his body and ME in a different way when he is playing golf or skittles and which contrast the anxiety associated with Les's ME and the cemetery. I discussed this in terms of the places that these activities comprise and how Les's body is transformed as it becomes part of different these different psychosocial spaces. Part of this was how Les understands ME in relation to his aging body and its changing capacities.

Finally, I cited Latour (2004) to argue that the body, or rather a certain body or body part has to be brought into being, rather than representing a pre-existent whole, and that this occurs as a dynamic process that involves material objects and spaces.

Chapter 9

Summary of main findings and how they contribute to knowledge, evaluation of the methodological premise, limits of the study and suggestions for further research

9.1 Chapter overview

In this final chapter I summarise my research findings and the contribution they make to understanding the experience of suffering ME and its relation to self. The central premise of this research was to develop a non-reductive means of exploring ME and its effects on self in relation to the material environment and the objects in it. This premise was formalised as three research questions that I approached by developing a methodology built on a synthesis of Actor Network Theory and psychoanalytically inspired psychosocial ideas about metaphor and metonymy:

- How can material actants be used to explore the relationship between self and others for people with ME?
- How can metaphor and metonymy be used to explore relations between actants?
- Can ANT and metaphor be used to rethink how the body is theorised in ME?

A key concern was to find a way of identifying all the different types of things that ME might be comprised of, such as viruses, symptoms, discourses, life events and material places on an equal footing. The purpose of this was to avoid slipping into an implicit causality where one thing was assumed to be more important than another and hence determinate in how ME took shape. ANT became the means by which this was achieved because it adopts a relational ontology, which enabled me to approach each entity [actant] as equally significant. Through the ANT premise of *translation* this provided an heuristic to think about what each actant was doing in a sufferer's experience of ME in terms of its associations with other actants. Using translation enabled me to build up an understanding of a given sufferer's ME in terms of *networks*. I defined the term *local* and *global networks* to describe the analytical process of organising the associations and actants that became salient into overall descriptions of how ME was manifested.

A significant idea within the ANT notion of translation is that an actant becomes *displaced* from one site to another, across place and time and in terms of form. It was important to trace these displacements and to account for them so that the resultant descriptions of ME could be substantiated. To explore associations I drew on psychoanalytically inspired psychosocial approaches. Such approaches enable an equal-handed treatment of the social and psychological aspects of ME and promote creative ideas about the relationships between psychological and sociological processes and their mutual infusion. Most importantly, psychosocial approaches challenge the notion of the rational and autonomous human that characterises social understanding as well as collapsing dualistic notions of mind/body; which the ME debate largely hinges on. In contrast, a psychosocial focus is on process and relationships and exploring the unconscious ways in which the psychic infuses the social and vice versa. This lead to a thicker description of how ME is experienced.

Exploring psychosocial ideas lead me to research on metaphor and metonymy. The appeal was that contemporary work such as that of Lakoff and Johnson and psychoanalytic work by Freud, Klein and Winnicott appeared to converge on the idea that metaphor was intimately related to the way that humans develop language and thought through processes that primarily involve somatic and physical experiences that are situated in the immediate environment. I thus looked to metaphor as a means not only of tracing associations between actants but also to think about the connections between the body and materiality.

Finally, after building my ideas of how ME was related to the sufferer's material objects and environments I used the term *assemblage* to convey the messy complexity and indeterminate nature of ME and its effects on self. Assemblage captures how ME is comprised of concepts, experiences, viruses, bodies, material objects and places as a shifting mass of disparate actors in dynamic association. From this perspective self and identity become properties of the assemblage as a whole and not fixed, essential entities. Describing ME as an assemblage also captures the particularity of how ME is different for each sufferer; a further central imperative of my research.

The ethnographically inclined methodology that I developed was innovative and reflexive and involved bringing together many strands of data such as talking and participating with ME sufferers in their everyday environments and routines across a six month period. The challenges in developing the methods through which my

methodology was realised were many and included being with people who were emotionally and physically affected by ME and reconciling this with the requirements of research, the logistics of visiting sufferers across relatively long distances and capturing and organising vast quantities of data.

The analytical process was complicated and time consuming. The challenges included identifying whether instances in the data represented figurative, metaphoric or metonymic processes, substantiating my inferences and building up networks to the point where they were stable enough that I could begin to comment on how ME was entangled with self.

The end product of my research, this thesis, represents only a fraction of the material that was gathered and the time and work that actually took place. As my analyses are organised around three ME sufferers, the voices of remaining sufferer's are largely unrepresented. I feel this to be a significant issue requiring explicit acknowledgement.

9.2 Summary of main findings and how they contribute to knowledge

In this section I summarise the main findings of my research and how they contribute to an understanding of ME or as a psychosocial approach. The overall contribution is that my analyses reveal how ME is fundamentally entangled with material objects and environments and marked by unconscious processes and associations that might otherwise go overlooked. Also, exploring how the body can be theorised in terms of its parts and associations highlights the way that ME manifests in superficially similar ways that belie different and particular processes.

9.2.1 *Material actants and ME*

A key concern of this research was to explore the ways in which material actants were involved in the everyday experiences of ME sufferers. I was surprised by the range of things that ME sufferers showed me and this reflected the highly personal functions that these objects performed. In terms of method, focussing on objects not only facilitated and opened up the discussion with sufferers but quickly lead to an understanding of how their experience of ME was anchored in concrete reality. This was exemplified clearly with Bruce and the manner in which his relationships and how he narrated his self-understanding across his life span incorporated objects such as his Dad's cupboards and bench, his pill dispenser, his juicer and blender and bread and butter pudding. Exploring these objects as actants and tracing their associations

provided a means of connecting up experiences in Bruce's childhood as well as their ongoing effects. It also connects ME directly to the material environment and this focus is a novel contribution to ME research.

Considering material actants provides a means of tracing associations across time. They also reveal the type of varied and unconscious work that might be involved in managing ME in that the cupboards and bench provided a site on which Bruce could not only maintain contact with his Dad but also an opportunity to reject and resist his classed origins and emotional background. In this light, exploring material actants provides a means of thinking through how emotion and class have become conflated for Bruce. By connecting material actants with non-material actants and approaching them as a network enabled an understanding of how Bruce's material surroundings became displaced into a sense of class, which became conflated with burgeoning emotional alienation from self and parents. Overall Bruce's sense of otherness and emotional alienation from self and others became potentiated in many non-material and material actants and realised as an identity at the network level. The significance is the connection of this to Bruce's ME, a major feature of which appears to be a conflation between ongoing anxiety and emotion.

The significance of material actants to ME was illustrated by Bruce's pill dispenser, which validates and materially mediates an aspect of Bruce's ME experience. The effects of ME are thus associated with specific material actants. As such, the dispenser is granting Bruce an agential means to address his ME. This was also the case with the blender and juicer which became a site where Bruce can approach ME by utilising his scientific knowledge. The dispenser, juicer and blender enable Bruce to objectify ME and to distance himself from it.

From the ANT perspective, aspects of ME appear to be resolved by passing through specific material objects (González, 2013). For instance, in this manner, some of the anxiety associated with Bruce's symptoms is managed. Thus, anxiety can be thought about as the associations between things rather than as a thing in itself or as the contour between actants. This provides an alternative to deploying for instance anxiety as a thing in itself that exerts a causal effect, as from the biomedical perspective.

Using metaphor and metonymy to explore the relations between spaces, places and ME provides a radical understanding of the condition. In chapter seven I outlined the notion of debilitating space; a useful way of framing how a place can exacerbate or add to the negative effects of ME. This notion complements existing work on enabling and restorative spaces and associates with different actants such as emotion, energy, pain and the body. Whimsy's flat represented a debilitating space where she felt trapped, isolated and fears dying alone. Exemplifying the synthesis between ANT and metaphor, I framed how Whimsy's flat represented metaphoric processes that transcended and connected what would otherwise be binary understandings of inner/outer, social/individual and material/immaterial. By tracing chains of displacement I suggested that Whimsy's flat had become a metonymical translation of how she felt trapped in a body that did not work, due to ME. The relationship with her flat reprised how she experienced self as separate and yet internal to her body. This is a crucial insight into how the connections between body, self and the environment can be understood in terms of conscious and unconscious processes.

Whimsy's flat as debilitating also connected to traumatic events in Whimsy's childhood. Whimsy used meditation to ground her body and keep the traumatic event out of her flat. A debilitating space is therefore a space where past events and present practices converge. The notion extends and complements work on enabling spaces because it stresses the psychosocial relations between people, places and events rather than merely focussing on the material properties of place (Steinfeld and Danford, 1999) or their psychophysiological or social aspects (Korpela et al. 2008; Cattell et al. 2008).

The notion of debilitating space also applied to John in that he felt obliged to escape mounds of paper and how his flat symbolised lack of status and failure. With Hannah, whilst her house was facilitatory, outside the house had become a debilitating space where she suffered anxiety associated with social interaction and the fear of such interaction being compromised by ME symptoms. Thus, three different experiences of debilitating spaces suggest that not only is the notion useful in exploring the relation between ME and place, but it also points to the particularity of ME experience. The notion of a debilitating space provides a frame for exploring physical environments

where material and non-material actants interact with specific material places in non-causal ways.

The relationship between space and place and ME was also important for Les, but not in the sense of debilitation. I described the associations between Les's onset of ME, his fear of relapse, how his heart had stopped and how he regularly visits the cemetery behind his house. His conscious use of the cemetery is for exercise and fresh air. However, Les's relation to the cemetery can also be explored in terms of a site that involves specific unconscious anxieties concerning death and his heart that are inextricably linked with how he experiences ME. With John, I described how a specific cinema and his daily route past it could also be framed as a psychosocial space. I drew on Pink (2008) to think about a place not as a distinct, static area but as a process that implicates a mobile, sensing body, objects and others. This demonstrates not only the value of connecting ME to space and place but also the use of metaphor to trace such associations.

Overall, exploring ME as situated in specific places and rethinking them in terms of psychosocial spaces provides a lens on the types of activities ME sufferers might engage in and why, as well as highlighting the interplay between conscious and unconscious processes that may appear to result in counter-intuitive behaviour. It provides an alternative view that complements a rational understanding of activities designed to ameliorate ME, such as exercise.

9.2.3 *Understanding the relationship between antecedent events and ME*

Various behavioural, cognitive and biopsychosocial models of ME exist³². The commonality of these models is an implicit causality between antecedent factors such as biological triggers and behavioural and cognitive modes of maintenance. However, debate remains as to the weight that individual factors lend to how ME manifests or is maintained and thus what should be prioritised from a treatment perspective (Maes & Twisk, 2010). Models that seek to balance biological factors with the phenomenological experience of ME, such as Ulvestad (2008), where the problem is couched as a 'developmental systems disorder', are valuable in working to bridge the divide between biomedicine and qualitative social scientific accounts of ME. However,

³² See for example Surawy et al. (1995); Ulvestad (2008); Harvey & Wessely (2009); Maes and Twisk (2010) Moss-Morris et al. (2011).

they call uncritically on eclectic ideas such as psychoneuroimmunology, genetics, and phenomenology and systems theory. The problem is that because neither a common language nor ground had been established between these areas. It is therefore still not possible to attribute aetiological roles and there exists epistemological incompatibility.

The purpose of my research was to explore the relations between antecedent factors and the ongoing experience of ME from a non-causal, non-aetiological perspective. Thinking about antecedents metaphorically overcomes the problem of assuming causal relations between things or identifying the relative weight that might be attributed to factors. Because metaphors exist and cluster in complex ways it cannot be presumed that any metaphor or metonym represents a discrete, causal mapping between one thing and another (Kimmel, 2010). This in itself steers away from trying to establish linear relations between antecedent factors and towards thinking about factors as coincident or coextensive.

For instance, I outlined how Les narrated the onset of ME by conflating two apparently disconnected events, namely his heart stopping in 1991 and the [unusual] onset of ME with chest pains. Rather than establish causality between these events I approached them by tracing how these were associated with other actants. That there are associations were evidenced by Les's use of figurative language when describing the events. I used psychoanalytic ideas to consider why Les neither made a conscious connection between these events nor at any time mentioned death or dying explicitly. It was as though the anxiety associated with these events was displaced. I outlined the relationship to psychoanalytic ideas where unconscious anxiety that cannot be verbalised or expressed symbolically manifests as an apparently disconnected somatic symptom (Elisha, 2011). Perhaps this was why Les consciously acknowledged how he feared relapse; an event that appeared to metonymically reprise the issues with his heart and ME-onset. However, Les's heart stopping and his peculiar ME-onset are not easily reconciled with standard ME discourse or biomedical approaches. This indicates the use of a psychosocial framework and how it avoids reducing psychological symptoms to biological antecedents.

The complex nature of metaphor was also reflected in how Whimsy described antecedent events and brought to mind how metaphoric processes can become complexed into one object or process (Montana Katz, 2011). Moreover, the manner in which metaphors complex with each other can be conflicted and contradictory and this

was reflected in the way that Whimsy's narrative often felt compounded and confused when she described her triggering event. By using the ANT/metaphoric methods to follow and trace actants and their associations I outlined how Whimsy's understanding of the immediate triggering event appeared to be compounded with undisclosed childhood trauma, abandonment, a car crash and a lost baby amongst others. By using metaphor creatively and tying it into further elements of Whimsy's narrative, ME revealed itself as the associations between actants. I suggested that via a series of metonymic equivalents, death had become associated with unconscious fears that manifested physically in her neck and that her neck had become the focal point and embodiment of her ME.

Overall, exploring ME antecedents in terms of metaphor provides a way of incorporating things that might have otherwise been overlooked and leads to an appreciation of how temporally distant events remain important in the ongoing experience of ME and how they become conflated with specific physical entities and situated experiences.

9.2.4 *The particularity of ME and the heterogenous body*

The body is implicated in debates around ME in many ways, such as the contested mind-body aetiology, the debilitating nature of physical symptoms and politically motivated discourses about how to treat ME (Horton-Salway, 2001; 2002; Karfakis, 2013). There is also a tension between an increasing acknowledgement of the heterogeneity of ME and the biomedical tenet that similar illness manifestations must have something in common (Ulvestad, 2008); a key principle in separating out illness categories.

Ulvestad acknowledges, albeit from a systems viewpoint, that all people are different. The issue for Ulvestad is that individuals are diseased in their own way and that this defies essentialist approaches to management. I concur with this sentiment and Ulvestad's general premise which resonate with my research aim of using ANT and metaphor to rethink how the body is theorised in ME.

I have already described how I rethought the relationship between body and material places in terms of the displacement between Les's heart stopping, fear of relapse and the cemetery. But it is also important to emphasise the heterogeneity of the body itself in that ME for Les involved chest pains and headaches. For Whimsy, her neck became

the site of her ME because it blocked energy flows and inhibited romantic relations due to Whimsy's anxiety that it might break. Subjectively, Whimsy usually experienced her entire body as ungrounded and also undergoes what she describes as out of body experiences. John experienced headaches associated with waking up in his flat every day.

These descriptions point to the *particular* ways in which ME is experienced and that rather than an homogenised whole body affected by ME, ME is registered in parts of the body in both a metaphoric and literal manner. Adopting a relational ontological stance was crucial. The relational ontology of ANT decentred the body and allowed me to explore how it was affected by ME as a whole and in terms of its parts and at the same ontological level as other actants that became salient. In this manner the body and body-parts took on specific identities reflecting associations with specific actants. The specific arrangement of actantial associations potentiated the various identities of the particular body or parts therein and always in a particular context.

My descriptions of how ME affected the body/parts of the ME sufferers I worked with were therefore embedded in embodied practices and material contexts that could not always be articulated by the sufferer (Pink, 2011). By not assuming that similar processes underpin the experience of ME, despite similar surface manifestations, and by approaching ME indirectly provided a sense of how the condition is entangled and inseparable from the body and its particular material and non-material associations. I approached the body as simultaneously biological, material and physical and irreducible to social classification (Shilling, 2003).

The relational ontology of ANT contributes to decentring the body and re-envisioning it as one actant amongst many at the same ontological level. In this sense, the body becomes an effect at the network level or an "ambivalent form of materiality" Mulcahy (2012; p.82) yet one that acts and performs in particular ways depending on what it is assembled with. Thinking about the body as an heterogeneous assemblage reflects Birke's (1999) observation that the organic body is always in a state of flux, as cells and tissues are renewed and broken down. This actual heterogeneity coupled with metaphors of fluidity and translation contrasts the notion of the body as fixed. It is most apt given the unpredictability of the body in ME (Travers & Lawler, 2008).

Low energy and post-exertional malaise are common features of ME as well as psychiatric and biomedical concerns with characterising and managing the condition (Carruthers et al. 2011; Heins et al. 2013). Exploring the ways in which ME sufferers experience and understand energy is highly salient. Previous work reveals that ME sufferers characteristically deploy conventional metaphors about energy, for example:

“‘It’s like someone has sucked all your energy out with a big syringe”
(Brocki, 2008; p.250).

Or as an object:

“‘I think I’ve definitely got my base energy levels up.’ (*ibid.* p.260).

Energy is reported in terms of a quantifiable amount that can be depleted (Dickson, 2004; p.87). Besides energy being quantifiable and objectified, it can be given and taken in that:

“‘I can get energy from people and when they go they take my energy.’” (Hart & Grace, 2010; p. 193).

And lack of energy affects sufferer’s ability to maintain social contact (Reynolds & Vivat, 2006).

Hart and Grace (2010) note that a discourse around energy exists that is useful for analysing issues of fatigue. However, the manner in which this discourse is called upon appears to reflect the conventional, objectified use of energy mentioned previously. Moreover, the majority of qualitative social scientific literature that report ME narratives and the effects of fatigue and energy also call upon the same unproblematic discourse of energy as a quantifiable, objectified entity that can flow or be blocked. These conventional metaphors of energy were also reflected by sufferers in my research.

However, tracing associations using the ANT and metaphoric approach revealed a complex and conflated use of energy with the body, material actants and the material environment. Whimsy does not assume that energy is a mind or body phenomenon and relates to energy as a metaphor that enables her to articulate and experience the relationship between her neck, ME and actants such as the collapse. The blurring of

the literal and the figurative is revealed because her neck is a real part of the body but it blocks the flow of energy.

Whimsy is unclear to herself what energy is and describes it in metonymical terms of something that needs to be moved but cannot because of a compromised neck, which she fears might break. Thus, her use of energy at one level reflects conventional metaphor. Yet at another it points to a different relationship between factors that cannot be articulated by Whimsy. This indicates that energy is more problematic in how it is deployed and what it reveals. For instance, Whimsy narrates that energy is trapped in her head, which mirrors her fear of being trapped in her flat. But both of these instances of being trapped associate metonymically with early childhood trauma.

Approaching energy and ME for Whimsy through an accepted discourse of how energy is deployed may not reveal how her experience of ME is highly entangled with early experiences and the ongoing material environment of her flat. For John, the conflation of physical and psychological aspects of energy was explicit but energy was metaphorically translated into paper items which he ostensibly hoarded to inform him of the best decisions to make. However, John had become overwhelmed by the amount of paper which had translated itself into not making decisions. Consequently, he awoke each morning feeling overwhelmed and ‘lacking energy’ and his recourse was to escape his flat, which he did every day by taking the same route through town. For John, energy reflected associations between place and behaviour and hence ME. Overall, identifying the particular, non-conventional ways that energy is deployed and tracing its associations to material actants and environments enables new meanings about how ME is experienced and what it is comprised of to emerge.

9.2.6 *Exploring how self is affected by and associated with ME*

Whereas biomedical approaches to ME are concerned with aetiology, mechanisms and treatment, they are not concerned with what it is like to experience ME nor how it affects the self. Social scientific qualitative approaches to understanding what it feels like to suffer ME adopt various epistemological perspectives but tend to rely on standard discourses with which to describe its effects. They also tend to rely on the interview method as the mainstay of investigation. Because ME appears to transcend characterisation as psychological, social or physiological and because many aspects of ME are confusing and contradictory I envisaged ME in terms of a complex, dynamic arrangement of factors. I attempted to develop a perspective on ME and its effects on

self that rearticulated the mind-body schism and to account for the way that self experience might implicate the material world and environment by drawing on psychoanalytically informed ideas.

It was also important to develop a reflexive stance that incorporated the role I played in making sense of sufferers' narratives and my response to the research. A psychosocial approach appeared apposite. My analyses suggest ways of thinking about the entanglements of ME and self. For example, I described a particular arrangement between Bruce and specific actants that resulted in what I termed the *productive self*. This term captured how certain actants are mobilised so that Bruce can address ME symptoms such as fatigue and offset the anxiety associated with appearing unproductive in the eyes of others and to himself. Through cooking, Bruce has been able to explore his relation to ME by incorporating an ideology inclined to harmony with nature and natural things. He has utilised specific material actants such as a blender and a juicer that have become significant signs of the self (Rochberg-Halton, 1984). The blender acts as a displacement of Bruce's lack of strength and wrist weakness. Methodologically, the blender facilitated a discussion about Bruce's food intolerances. This in itself indicates the importance of utilising material objects as a means of theorising the self and opening up dialogue about self experience. More importantly, my analysis attempted to illustrate how self can be thought about as emerging in light of the ways that specific actants associate.

How Bruce experiences ME and how he understands it has affected his self reflects a particular arrangement of actants. This is in contrast to the generalising tendency of existing social scientific qualitative research to present alternative, sometimes contrasting and yet quite general trajectories of the relationship between self and ME. Focusing on the ongoing movement between actants in and out of networks encourages thinking about the ways in which Bruce's self experience is anchored in materiality but is also phenomenologically different at different times, depending what is associated.

This psychosocial perspective challenges the idea of an autonomous self that is affected by ME in an objective, unitary manner because the perspective implies the entanglements between many disparate factors that have existed across Bruce's life and which Bruce is not consciously aware of.

My approach also sheds light on the relationship between ME, self and real and imagined others. With Whimsy, I described how her metonymic relation with her neck and fear that it might break affected her ability to embark on romantic relations. This aspect of self experience is a clear example of how ME affects social relations in a general sense, but that a psychosocial perspective reveals an arrangement of actants particular to Whimsy. Overall, the psychosocial framework I have developed has enabled an exploration of self and ME by incorporating factors that might otherwise have been overlooked. My analyses reveals that the relationship between self and ME is much more complex than existing research might suggest.

9.3 Evaluation of the methodological premise

Given that my research involved developing a methodology through synthesising existing ideas, it is important to evaluate the viability of some of the central methodological aspects. Whilst there are clearly many features that require evaluation, the scope of this thesis precludes it. Thus, I evaluate what I consider are key issues. These are the success or failure of adopting a relational ontology, whether ANT lent itself to being synthesised with ideas on metaphor and whether the methodology is capable of exploring issues of otherness in ME. The last issue is significant not only because of the ubiquity of the human experience of otherness but also because it characterises many aspects of ME.

9.3.1 *The issue of ontology*

Establishing a relational ontology was employed so that I could explore all actants as equally significant to the experience of ME and how ME sufferers constitute their reality, without restricting my focus to one type of actant or to adopting a specific epistemological stance.

According to Wildman (2006), the basic contention with a relational ontology is that the relations between entities become more important than the entities themselves. Wildman also points to the need to think about the ontological prioritisation of substance over relation, given that situations exist where a relation will change but the substance will not. A further consideration is whether relations are ontologically real or merely attributions made by conscious entities. For instance, an idealist stance would attribute primary ontological status to conceptual relations and from an empirical perspective, causation provides an ontological basis for speaking of the

reality of relations, which means causal relations exist irrespective of whether people are conscious of them or not. Ontology is therefore important concerning ME if it entails, for example, relations involving a virus that are independent of people's conscious engagement with it but which do have a casual effect. Therefore, a question is whether I have downplayed relations which might be better thought of as causal or which might conflict with the understanding that ME sufferers hold.

By assuming ontological relationality between actants I could focus on the associations between things in an inclusive manner. In line with Gargiulo (2006) this fits with the notion that ME has no single centre of meaning or single causal entity. Instead, ME constantly circulates, is redefined and renegotiated. So there exists a tension between the poles of causality and coextensivity that perhaps reflects Latour's (2005; p.147) claim that actors establish their own ontologies. In other words descriptions of how actors' worlds become established take precedence over the explanations of [social] scientists. From this perspective, the relational ontology I adopted served as a useful means of retaining the importance of all actants but what is equally important is valuing how ME sufferers construct their experience on their own terms.

A further justification for adopting a relational ontology is because the ontological problem is not directly addressed by biomedical ME research. Instead, the focus appears to be epistemological. But as Poli (2002) notes, it is unreasonable to address a scientific problem without at least considering its ontological boundaries and structures. Ontological neglect is a core issue with existing biomedical research into ME because of implicit assumptions about causal relations. The categories that biomedicine attributes items to, such as physiological, psychological and psychosocial, represent ontological domains that become entangled in complex ways and therefore difficult to tease apart and analyse in terms of the implicit causality of biomedical epistemology. Looking for root causes of ME results in ambiguity. Categorising ME also means anything that does not immediately fit into a category is in danger of being discarded in the analysis. For instance, John's collection of paper is clearly entangled with his ME symptomology but it does not fit neatly into a biomedical categorisation of ME and is at odds with the formal diagnosis of ME which he has. It may however fit into a psychiatric category, but that exacerbates the problem.

However, I do acknowledge two issues. Firstly, the criticism that a relational ontology, by equating inanimate objects with humans, relegates the latter's agency and lived

uniqueness. Mutch (2002; p.487) states that a relational ontology fails to escape the level of process and “ignores the stratified nature of human society”. This implies that people are reduced to the effects of their associations. As Sutherland (2013) notes, concepts such as ‘process’, ‘flow’ and ‘flux’ are unable to account for the material substantiality and agency of objects and privileges ‘becoming’ over ‘being’. However, this type of criticism is tautological and implies the dichotomy of process and object that I sought to avoid.

My position is that processes implicate objects and vice versa and are therefore inseparable. Concerning ME, a virus may be implicated but that implication is in the form of an embodied effect and a process that also entails other objects. The virus cannot be distinguished as separate from the mental constructs and methods used to make sense of it or how it is experienced (Pels, Hetherington and Vandenberghe, 2002). Because a virus cannot be experienced in an unmediated and unrepresented form there is no recourse to a deeper ontological level of reality. In this way, I argue that human experience is a process always mediated by things but because of the subjective sense of self the ‘things’ become bracketed off as separate from us. My conclusion is that a relational ontology was warranted. But it does lead to the observation that despite the suggestion that things and people are equally significant, most people feel more important than, for example, a food mixer. Thus the lived experience and subjective understanding of ME is paramount and research should therefore seek to maintain the integrity of sufferers’ accounts by avoiding the imposition of a version of ME on them.

In summary, the ontological stance I have adopted allowed me to extend an understanding of the experience of ME. It enabled me to follow disparate actants and explore the processes and relationships ME entails from the perspective of otherwise neglected entities and through which ME is experienced and made sense of. It provided a useful way of grounding my psychosocial framework. However, in the spirit of ANT I emphasise that the descriptions of the ME sufferers I worked with remain paramount on their own terms.

9.3.2 *The compatibility of metaphor with ANT*

In this section I evaluate my synthesis of ANT and metaphor, outlining where I think the synthesis was successful and raising points of concern. My rationale for this synthesis was that I wanted to retain a sense of the interiority of self without reducing

it to an exclusively inner process and to connect up the disparate aspects that constituted ME. Psychoanalytically informed psychosocial approaches provided a means of thinking about the relationship between mind and body from an already metaphorical perspective. ANT provided a non-reductionist framework from which the associations between different entities could be explored.

The flexible nature of metaphor implicitly acknowledges the potential for multiple associations between actants and points to the contingency of these associations and away from positing essential connections or causal relations. In line with Latour (2005), using metaphor encourages resisting the familiar and being creative. Was this in keeping with the basic ANT premise?

An initial concern was that metaphor represented a separate ontology, with the implication that metaphorical relations, even if hidden, are substantive. However, metaphor was being used to suggest and describe potential associations between actants and their identity in relation to the whole network. It was not being used to describe essential qualities of actants. This means that the metaphors used to talk about associations were also potentialities of the actants themselves. However, there may remain some tension between the use of metaphor, which represents an idealist position, and the materially orientated relational ontology of ANT.

If metaphor development and use is not intimately associated with somatic and physical extra-somatic experience then it operates in an ontologically different domain from the body and the material environment. If this is the case, then my recourse to a relational ontology that grounds the body, the material, the experiential and the conceptual is flawed in a way that negates the methodological premise. That is a strong version of the problem. The weaker version is that whilst I am uncertain about the degree to which thinking and experience are metaphorical and the degree to which metaphor develops as part of physiological development, it does provide a useful heuristic which enabled me to describe how actants associate and why certain actants constellate. But there remains an issue of not overstating the case or promoting metaphoric relations to a position of causality. For instance, Les's heart stopping has a metaphoric relation and a literal one to being dead. But that does not mean that there existed some underlying metaphoric process that structured these relations, as implied by psychoanalytic writers such as Montana Katz (2001) and Borbely (2004, 2009). In other words, I am not establishing metaphor as a separate ontology.

A further issue is that I tended to assume that metaphor reflected functional relations with objects. For instance, I have looked at what Bruce *does* with his food blender and did not enquire about its metaphorical status directly. I assumed that objects possessed some literal properties and metaphorically others (Goodman, 1979; Shottenkirk, 2009) but tended towards the functional. Stern (2001; p.302) debates the metaphorical status of non-linguistic objects, he explains that the broader issue is about the mechanisms that are specifically responsible for metaphor as opposed to general mechanisms concerned with symbolisation in a broad sense. In other words, are metaphoric processes a special subset of symbolisation and is there a case for focussing on literal relations? These questions require further work. Beyond this there exists difficulty in assessing whether material is metaphorical or metonymical, or indeed overlaps, in the first place (Bartsch, 2002; Dirven et al. 2003).

Using metaphor to think about temporal relations proved useful. Incorporating metaphor as the means of establishing associations provided a means of noticing and thinking about temporal associations. According to Cameron et al. (2009), metaphors leave traces behind them or trails of association. This implies the temporal and spatial aspects of metaphor and that metaphors connect many systems of thinking, language, discourse and various levels of social organisation. Cameron et al. (2009; p.64) sheds some light on this by thinking about metaphor as:

“No longer a static, fixed mapping, but a temporary stability emerging from the activity of interconnecting systems of socially-situated language use and cognitive activity.”

This is commensurate with an ANT perspective because it means that metaphor is not viewed as a separate ontological level that stands behind actants. This perspective also resonates with my psychosocial framework in that metaphoric structures transcend inner/outer divides and bring together otherwise disparate elements yet in a dynamic manner.

But it is still the case that some metaphoric translations are more conventional and hence less opaque than others. Glucksberg and McGlone (1999) raise the question of how to decide which attributes of a metaphor's source equate to attributes assumed from its target. For instance the metaphoric translation Whimsy's wooden peg and a lack of father figure is initially opaque. Gildea & Glucksberg (1983) assert that whilst some metaphors are immediately understandable, others require an appropriate context

to trigger comprehension. Similarly, Stern (2001) argues that semantic context systematically affects how metaphoric interpretation occurs. So questions remain as to why certain metaphoric relations are established from the perspective of the ME sufferer and whether these reflect a further level of organisation.

The breadth of what is considered as metaphor also needs to be addressed. To suggest linguistic similarities rest on a conceptual system where experiences in one domain can be understood metaphorically in terms of another domain rests on a definition of metaphor that is 'so broad that it loses its original valency' (Jackendoff and Aaron, 1991). Perhaps this indicates not only a difficulty in separating out metaphorical, metonymical and literal material but the reflexive issue that ultimately any interpretation rests with the researcher.

In summary, my basic premise that metaphor provides an heuristic means of tracing the associations between actants and provides a descriptive language to talk about association appears warranted and in keeping with ANT. However, questions remain about why certain metaphoric processes become salient and not others, which requires further exploration. There may also be a case for paying more attention to the literal, functional relations between ME sufferers and material actants and environments.

9.4 Possible limitations of the research

In this section I discuss the possible limitations of my research and thesis. These fall into two main areas. These are issues with generalisability of the method and issues of reflexivity.

The first area hinges on my sample size and the premise of describing the particularity of ME. Firstly, it might be argued that eight ME sufferers are too few to provide an adequate basis to assess the generalisability of the method and as such it provides a limited view of the general experience of ME. However, given that my rationale involved the development of a new methodology, a small sample size was warranted. More importantly, the methodology rested on prioritising the experience of the ME sufferer and wanting to gain in-depth insight, over time, into their experiences, daily routines, sense of self and the particularity of ME.

It was also necessary to employ a small sample because of the projected amount of data that would be generated and how this would limit the degree of analysis that could be achieved in the given period. Whether my analyses provide general descriptions of

how ME is related to self experience is less clear. Indeed, the sufferers I worked with narrated many similar and general experiences with ME that reflect accepted discourses on the condition.

For example, ME had a social impact in every case. However, given my focus on the particularity of ME, sample size is irrelevant. But there remains a paradox. On one hand, my approach allowed me to explore ME from an experience-near perspective, which was novel in itself and lead to descriptions of how ME and its effects, whilst superficially similar, arose through very different processes. On the other hand, from this perspective it is difficult to draw comparisons between cases of ME. I conclude that the effectiveness of my premise and methods should be judged on the merits of my analyses in this thesis and their potential transferability and not on the generalisability of my findings concerning ME.

Another aspect of generalisability which is more problematic is that the sample was comprised of ME sufferers who were mobile and well enough to participate and past an acute and extremely debilitating onset, where sometimes the sufferer is bed-ridden. The reasons why I worked with an able sample reflect sampling techniques and the nature of the sites from which I recruited as well as the ethical concern for their well-being. Thus, the experience of sufferers at the time of research would be vastly different from their experience at acute ME onset. Sufferers at the acute stage would be less mobile and perhaps engaged with the material environment in a different or limited way. In cases of extreme fatigue and cognitive impairment this would affect the researcher's ability to engage with the sufferer's day to day experience and converse with them in. An issue which results from this state of affairs is that more consideration needs to be given to whether the methods could indeed be used with more debilitated sufferers. However, that is not to say the general premise of the methodology could not be applied.

In terms of the trajectory of ME, a significant improvement could be achieved by extending the study period to a year or longer and with more data collection points. Whilst this would result in an even larger corpus of data to manage it would allow exploration of more of the illness trajectory and a shift in focus to how the self changed across the period for a given sufferer.

The issue of reflexivity is a double edged sword. On the one hand, I explicitly situated myself as an actant in the sufferer's network and became part of their lived experience

of ME. The analytical justification was that my subjective relation to research visits and the sufferer's experience involved establishing myself as an actant in the sufferer's experience of ME. From this position and by association with actants in the sufferer's world, I could explicitly acknowledge my role in translation and interpretation. For instance through my affective response and how this informed 'following the actor' and feeding my responses back to the sufferer where applicable.

On the other hand, it can be argued that if a different researcher established themselves as an actant in the research process and given that each sufferer is an individual with their own potentialities and history, then each analytical interpretation will be substantially different. I would argue that should not be the case as long as the conceptual and methodological spirit I developed was adhered to. For instance, it should be the case that any researcher working with Bruce would arrive at an observation of significant actants such as his blender and could connect this to being productive. So whilst the nuances of the interpretation might vary, the broad perspective should be similar.

9.5 Personal reflections

Personal reflection enables an assessment of the researcher's self and identity in relation to the participant and research process as a whole (Hand, 2003). Jasper (2005) explains that researchers should also examine their biases and prejudices so that they can understand how they have influenced the research. Jasper also claims that by uncovering one's own background, the trustworthiness of the research is enhanced because addressing one's background amounts to acknowledging the centrality of the researcher in the research process. This reflexive position is commensurate with the ANT-informed stance I adopted. It was necessary to bear my own prejudices in mind, given that my personal experience with two consecutive partners who each had ME had lead me to focus on ME as a research topic. Thus, Pain and Francis (2003; p.46) note that participatory research:

“...is not so much the methods and techniques employed, but the degree of engagement of participants within and beyond the research encounter.”

The word 'beyond' resonates with me because my research became my life for several years. I would anecdotally reflect to people that it was the first thought on my mind when I wake up and the last thing I think of at night. This statement is quite accurate and reflects my degree of investment in the work.

As discussed in the opening chapter, at some point during the research process, what had been ‘participants’ became referred to throughout my thesis as “the ME sufferer” or “the ME sufferers I worked with”. This reflects how my subjective relationship with these real people changed as I moved deeper into the work and into their worlds. Indeed, my lead supervisor regularly pointed out the need to “keep the sufferer at the heart of the research”, but I only came to understand this after the fieldwork was complete.

At the end of this research I am left with mixed feelings. Primarily, a sense of frustration at what I perceive as the complex task of engaging with subjectivity and understanding the life world of another and to express that understanding in a way that does it justice. This may indicate a deep level of anxiety that I cannot or do not want to engage with, which I return to below. Despite attempting to symmetrise the relation between human and non-human, or the phenomenological/feeling individual and the individual as assemblage, my analyses taken as a whole demonstrate a commitment to ‘real people’. Not real in that they are self contained monads but real in terms of how *my* experience is infused with *theirs*. This perhaps belies the difficulty in avoiding an inherent and perhaps unconscious dichotomy of how people are experienced; how one’s self is experienced. It implies perhaps the impossible task of keeping oneself and the people one researches affectively and unconsciously unentangled.

So the ANT/metaphor stance I developed and which allowed me to situate myself as an actant in the life world of the ME sufferers I worked with brings to mind Orange’s (1995) claim that much of what researchers do, methodologically, is designed to defend against unconscious anxiety and emotion. In this sense, becoming an actant enabled me to rationalise my emotional response but not to disengage with it. But in that light, and in ANT’s light, by becoming part of the network of the ME sufferers I worked with meant that they became part of *my* network. As outlined in the introductory chapter, my route into this research was via two personal relationships with ME sufferers. I have to ask myself the question: has my research altered how I feel about and understand the experiences I had with each of these people and their experience of ME? In light of psychosocial approaches such as that of Walkerdine, Melody and Lucey a concern is how explicit I could and should have been about my own feelings during the analytic process also required consideration. My conclusion, having completed the work, is that my feelings and the implication of my own anxieties, responses and so on *are present in the analysis* as it stands. My methods

involved recording my affective responses immediately after each visit, annotating transcripts with my feelings and thoughts as part of the process and so on. The implication is that reflecting on my experiences with the research and with the sufferers was present as an ongoing part of the process. As to whether it is possible to 'stay' with a feeling, enabling it to take a symbolic form such as a thought or a word, has to be viewed cautiously. This is because if one accepts any psychoanalytic premise then one has to accept that what we think is ultimately a distortion to one degree or another, effected by unconscious defences. The implication is that over reflection may in fact result in an even more distorted, rationalised or intellectualised version of what was felt. I would instead emphasise that 'being' is to allow oneself to be changed; a dynamic process.

As I reflect on this, I experience the impossibility of suspending the understanding I now have of ME and remembering and reimagining those relationships by going back to the understanding I did or did not have when I embarked on this research. This means I *have* been changed. But perhaps unsurprisingly, given that as Latour might note: to become an actant in a network is to allow oneself to be changed. What does this mean for ME research in a broader sense?

In section 5.3.8 I noted that in arriving at my choice of presentation of analyses, by selecting three individual cases, I had 'betrayed' those sufferers I had not represented in this thesis. The majority, 60 – 80% of ME sufferers are female. 5 out of 8 of the sufferers I worked with were female and yet two of the three cases presented in this thesis were male. The betrayal implied thus applies primarily to the female sufferers I worked with. My rational choice of cases was based on those which best illustrated analytical insights about ME but I have to consider how this relates to my position as a male researcher and how this might be implicated in my choices. It is also the case that the motivation for my PhD was based on my experience with two successive partners with ME. It is not appropriate to engage in second guessing the potential of latent, unconscious processes to have shaped my choices. But it is imperative to acknowledge that, whatever the motivations, how ME has been represented in this thesis inevitably does some disservice to the fact that ME is primarily reported in females and may, in a very critical reading, reinforce stereotypical views of ME and its relation to gender and discourses of power around it. This requires further exploration.

The ‘deep level of anxiety’ which I cited above I now recognise as displaced in two senses. Firstly, in my desire to follow up this thesis with research that develops a therapeutic application of my thesis which I can take back to the sufferers. In a phantasised sense, if I can help the sufferers I worked with then I can make reparations for the unconscious anxiety they perhaps evoked in me. Anxiety that may arise via the guilt I experienced in not being able to tell each and all of their stories. There is also something here about the inadequacy of the case study method I adopted in that no story can ever be fully told and this inevitably leads to a gap between how a life is experienced and how it can be represented. Secondly, I feel that what, nearly five years ago, appeared to me as pragmatic choices about how to choose a topic to build a PhD around [ME] and to ensure my proposal was accepted in fact had more to do with wanting to cure the people I had relationships with of their ME. This is also where I have changed.

I feel very strongly about how my work, how the relationships I have had with ME sufferers in various senses and my future proposal [discussed below] to extend my work into a therapeutic direction are themselves thoroughly entangled and yet how I can hold on to this entanglement because of what I have learned. Without detracting from what might be fruitful future work, the ‘psychoanalytic sensibility’ I sought to develop means that I am comfortable acknowledging on one hand that I believe I can develop this work for the benefit of others and yet on the other hand recognise my subjective investment in that and with the anxieties that circulate both consciously and unconsciously. This speaks of the broad phantasy that research and even therapy can ever be anything other than thoroughly psychosocial in the sense that I have used that term.

In a more transparent sense, perhaps my whole premise of associations, networks, assemblages and connections represent metaphorically an unconscious need on my part to be connected and to be part of something greater than myself. It may also represent an implicit resurrection narrative in that from my ANT/metaphor premise if nothing is really in the past then nothing really dies. This brings to mind Nitzgen’s (2004) claim that what brings people to their ideas is the way that personal experience and technology structures human relations. Nitzgen is referring to how for instance Bion served as a tank commander in World War One long before he theorised the paradigm of container/contained. Nitzgen brings the relation between our material environment and subjectivity to attention. I would make explicit that this also entails

an enduring affective relationship that involves the many other imagined actants that constitute one's ongoing life history.

9.6 Future directions

Very little psychoanalytically or psychosocial informed work has been carried out on ME beyond one or two cases studies. This was personally reported to me by Professor P. D. White, Professor of Psychological Medicine, Barts and the London School of Medicine and Dentistry, at the beginning of my research. Where psychodynamically informed models of ME aetiology have been proposed, the explanation for disease susceptibility is located with a failure of early maternal attunement, leading to later psychological and physiological vulnerability (Taerk & Gnam, 1994). Positing such causality is incompatible with my conceptual premise.

However, three sufferers explicitly stated that having someone to talk to in their home had been useful for them in terms of having their experience reflected back to them and through providing a space in which they could explain and explore their ME experience. As I have highlighted throughout this thesis and as Simpson et al. (1997) point out from a psychodynamic perspective, each case presents a 'unique mix' in terms of aetiology. Added to this is the uniqueness of each individual's lived material environment.

With this in mind, one direction this research could take is to inform a rationale for psychotherapeutic intervention in ME that takes the therapy to the sufferer, rather than as with all existing approaches which involve visiting a therapist. In line with this, the ANT/metaphor approach can be used to inform a protocol which enables the person to work through their relationship with people, places and things as contextualised in their home and everyday environments.

For instance, Whimsy was trapped in her flat and this may have been for many reasons including financial ones or because the flat was an actant acting in association with others metaphorically as I described. It might be beneficial, having identified this, to explore with Whimsy what this means for her and whether it or any actants associating with it can be re-constellated in a more positive way. Similarly with John, having identified his relationship with paper and his flat and how these associate with his need to literally escape from his flat might provide a way to explore with him what this means metaphorically and what can be done to redress the situation.

To date, most psychotherapeutic work takes place in a room dedicated by the therapist. The rationale for this developed from the need to contain the feelings mobilised during the therapeutic encounter (Gabbard, 1995). It also provided a clear boundary which aimed to prevent transgression such as sexual intimacy between client and therapist (Gutheil & Gabbard, 1993). However, recent developments in psychotherapy have explored practice in non-standard settings such as the home of the client and in what might be termed 'nature' or the countryside (Jordan, 2009; Jordan & Marshall, 2010).

A rationale for working therapeutically with people in their home, from the ANT perspective, is that the researcher or therapist enters that world as an actant and becomes part of the sufferer's experience and ongoing arrangement. Commensurate with this is the ANT/metaphor approach does not utilise pre-existing tools that inform various psychotherapies such concepts of true and false selves, splitting, and maternal misattunement and so on.

From a more theoretical perspective, it would be interesting to consider how the ANT/metaphor approach could be used to think about existing psychoanalytic concepts, given the focus on the relations between people and things. My rationale was to think about the confusing and conflicted aspects of ME and thus to consider unconscious processes without adopting an existing and specific psychoanalytic conceptualisation. Thus, further work can be carried out to explore the veracity of thinking about unconscious processes from the perspective I have described.

ANT has already proven to be applicable to a wide range of topics beyond its initial sociology of science, such as in medicine and care (Mol, 2002; 2008) and law (Latour, 2009). The ANT/metaphor as an extension of ANT could also be assessed in terms of exploring many other conditions that entail chronic illness to provide a different perspective on the particular experience of a given condition. The value in bringing the ANT/metaphor approach to the study of other conditions lays in the way that it brackets off social conceptualisations and specific discourses about the condition. Across the duration of this research I have noticed a move in ME literature towards establishing ME as an heterogenous condition. The ANT/metaphor approach is useful in that it can account for the heterogeneity of actants that such a condition comprises and this is likely to be the case for other conditions. It provides a tool that can be combined with different ways of exploring associations besides the metaphorical.

The scope of this thesis prevents many aspects of my research from being reported and indeed, many avenues of exploration had to be discarded along the way. For example, I worked on ideas about approaching ME from the perspective of transdisciplinarity; an area that appealed because it involves the production of new methods, new theory and new languages and results in an epistemological shift (Austin, Park and Goble, 2008) that reflects a growing concern with moving past dualisms. This avenue requires further consideration. I have not been able to report on what I envisaged as *functional adaptations*; a term I developed to describe how Les in particular had traded certain material devices for ones that helped him manage his ME without consciously realising it. Exploring this avenue would complement existing work on assistive devices³³ and their role in how self is experienced in light of other illnesses. Finally, as my research progressed I became aware that the nature of how research is reported in peer reviewed journals appears to be intimately linked with how epistemological stances are developed and how knowledge of ME takes shape. This inspired me to think about the etymological nature of theory development in general and why some concepts maintain inertia whilst others evolve or disappear. This resulted in a notion which I termed as *theory drift* (Fellenor, 2013) and whilst tangential to ME, requires further work.

³³ Assistive devices are items, pieces of equipment or product systems that are used to increase or improve daily occupation and participation in everyday life. See for example (Hägglom-Kronlöf & Sonn, 2007). For discussions on the relations between assistive devices and self-image see (Moller, 1999; Pape, Kim and Weiner, 2002; Lund, & Nygard, 2008).

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Appendix 1: participant information sheet

Bath University Psychology Department

Participant Information Sheet: Ref. 11-916

An Investigation of the Home Environment and how it relates to the experiences of People with ME

My name is John Fellenor and I am a second year PhD student with the Department of Psychology at Bath University. My research is about developing ways of understanding how the everyday physical environment and the real objects in it might relate to the way that you experience ME/CFS and how this in turn affects your sense of identity and how you feel about yourself.

This information sheet provides information about what is involved in taking part in this research.

What is this research about?

The background for this research is based on ideas about how people with ME/CFS understand and think about themselves in light of their experiences, beliefs and how the real world around us might play a part in that process. The main focus is on the role that might be played by everyday things found in the home.

What will happen if I decide to take part?

Because every day with ME/CFS can be different from the next, the research will last for six months and involves the researcher coming to your home for five separate visits. During each visit a different aspect of what it is like to live with ME/CFS will be looked at.

What exactly will happen each time the researcher visits you?

The first visit allows me to explain the research to you in more detail and for you to ask me any questions you may have about taking part. You will also be asked to sign a consent form which shows you agree to take part. After this, we will spend up to an hour or as long as you are comfortable with discussing your experience of ME/CFS and how this affects your day to day life. This will be recorded with a video camera.

Subsequent visits are outlined below:

Second visit:

- Open-ended discussion of how your home environment and the objects in it are important to you.
- An object can be absolutely anything you have in your home and have owned for a long or a short time.
- Video recording will be used as before.

Third visit:

- Involves you carrying out a short physical activity from your daily routine that you have previously thought about and chosen, which may include using an object or item like you would on any day.
- Examples include: washing up, cleaning, gardening, watching TV, DIY etc.
- You may like to choose an activity that I can also take part in.

- This session will be video recorded but the focus is the activity rather than discussion about it.

Fourth Visit:

- The activity for this visit will be something important to you that you choose.
- You may wish to do something similar to the previous encounter, discuss an issue that is significant for you or combinations of activity and discussion.

Fifth visit:

- Discussion of the overall process and completing some semi-structured questions about what if anything you feel has changed in your life-experience over the study duration; followed by a full debriefing.

At no time will you be asked to talk about things you don't want to talk about, show me parts of your home or objects you don't want to or choose to do any strenuous activity that you wouldn't normally do.

Why is a video camera being used?

It will be useful to video record our discussions and how you relate to your environment and activities because not only will it record our conversation but also what objects are like and how you use them.

Can anyone take part in this research?

Anyone can take part as long as they are eighteen years of age or older and have been *clinically diagnosed* with ME/CFS. You can take part, irrespective of your personal level of ME/CFS as long as you feel mentally and physically able to do so.

What will happen with the video recording and the notes you make?

No one apart from the researcher will have any access to video recordings or notes and these will be kept at all times in a securely locked cupboard.

Will people be able to tell who I am at any point during the research or from the written report?

No. At the start of the research period you will choose a pseudonym for yourself. You will be referred to by this name only in any writings or notes from that point onwards. No one will be able to link the written research to you at any point.

I have decided to participate. How will the researcher organise the research?

If you think you would like to take part then contact me by phone or e-mail [details below] and we can then arrange the first visit.

What if I decide that I don't want to take part or change my mind half way through?

You have the right to withdraw from the research at any time during the whole six month period. All you have to do is contact me to let me know you don't wish to carry on and you won't need to explain why.

If you choose to do this then all data relating to you will be destroyed.

What if I let you handle one of my objects or possessions and you break it?

Bath University are insured for damages to objects up to £200. This means that if you allow me to handle or use an item in your home and I accidentally damage it, it should be replaceable and not expensive.

The researcher is a PhD student at Bath University in the Psychology Department.

The researcher can be contacted by e-mail at XXXXXX@bath.ac.uk or by phone on 075XXXXXXXX.

Bath University Psychology Department can be contacted by e-mail at psychology-enquiries@bath.ac.uk

Appendix 2: Standard brief read to all participants before giving consent

Thank you for agreeing to take part in this study which looks at how material objects and the physical environment might be part of the relationship between self and others in people with ME/CFS. During this study you will not be asked to undertake any physical activity or any other activity that you would not normally encounter in your everyday life; as such, it should pose you no unusual degree of physical harm or stress. Any activities in relation to the study that you decide on undertaking will be entirely at your discretion as detailed in the information sheet you have been given.

Across the six month study period, comprising five visits from the researcher, you will be involved at various times in discussing your experience of ME/CFS, carrying out everyday tasks or routines with the researcher in observation or joining in at your discretion. The form of the discussions will be open ended and I will be asking questions about what aspects of the physical environment and the objects in it are important to you and why. In other words, we will be having everyday conversations where we can both ask and answer questions. I will not be asking you any questions or request any information of a personal or sensitive nature and you can decline to answer or discuss anything as you see fit.

As outlined on the information sheet you have been provided with, I will be using a video recorder on a tripod to record our discussions and images of the environment and objects you discuss. This means that you will appear on the video recording. During our conversation you may wish to tell me specific things you want me to write down and that is okay. I will not be making any notes at the time of our meetings but when the session has finished and I return home I will be making notes about things I feel were important or things you ask me to record. I have to ask you two relevant questions. If you answer yes to either question then unfortunately I will not be able to include you in the study as it may bias the results. Firstly, have you taken part in research like this before?

[wait for response and proceed accordingly].

Secondly, having read the information sheet and consent form are you able and willing to take part in this study?

[wait for response and proceed accordingly].

Thank you.

I must inform you that if during our research discussion and video-recording you disclose any information to me that leads me to believe you might be liable to engage in or have engaged in criminal activity or appear to be at risk of harming yourself or others then I will need to refer this information for advice to the relevant agencies and the university ethics committee.

In a moment, I will read with you the consent form. I will then ask you to sign that form which gives me permission to use you and the data you provide in the report that will be written about this study. In the written report of this research, stills from video sequences may be included but will be chosen to maintain anonymity. No individual will be identifiable from the data they have provided because all personal names will be anonymised and references to any specific places or events you have taken part in will be made impersonal. As such, your identity in the report will be totally anonymous and no person reading the report will be able to identify you from it. In terms of the

video-recorded material: no other person shall see this material apart from the researcher. Also, the objects you choose and will talk about will not be revealed to any other person and will be written about in an impersonal way so that they will not lead anyone reading the report to you. I must also tell you that you have the right to withdrawal now or at any time during the study, should you not wish to proceed. If this is the case then all you should do is tell me and this meeting will be halted; your data will not be included in the report. Do you have any questions that you would like to ask me about what you will be doing or about other aspects of the study?
[wait for response and proceed accordingly].

Ok. Here is the consent form to read and sign

[Give participant pen and consent form].

Thank you.

Appendix 3: Participant consent form

Bath University Psychology Department

Full title of project:

*An Investigation of the Home Environment and how it relates to the experiences of
People with ME (ref. 11-916)*

Name of principal investigator: John Fellenor

Please

initial box:

1. I confirm that I have read and understand the subject information sheet dated ____
for the above study and have had the opportunity to ask questions which have been
answered fully ☐

2. I understand that my participation is voluntary and I am free to withdraw at any time
without giving any reason, without my statutory rights being affected ☐

3. I understand that the research report will contain reference to and analysis of data
collected about me but that at all times this will be anonymised such that my personal
identity and information will not be discernible to others ☐

4. I am aware that all data relating to me will be anonymised at collection, stored
securely and destroyed at the end of the research and writing-up process ☐

5. Compensation arrangements have been discussed with me ☐

6. I agree to take part in the above study: ☐

Name of participant:_____ **Signature:**_____ **Date:**_____

Participant's date of birth:_____

Principal investigator:_____ **Signature:**_____ **Date:** _____

Appendix 4: Summary questionnaire

Name: _____

Onset and duration of ME symptoms

1 To the best of your memory, from which year/month can you remember experiencing symptoms which you now associate as ME?

____ years / ____ months

2 To the best of your memory, what was the year/month when you first approached a doctor or specialist about these symptoms?

____ year / ____ month

3 To the best of your memory, in which year/month did you first receive a diagnosis of ME?

____ year / ____ month

4 Have you ever followed an awareness or support course for ME from a specialist unit i.e. in a hospital?

____yes/____no

5 Do you attend or have you attended an ME self-help group?

____yes/____no

6 If your answer to question 7 was yes, what was the main reason you attended this group?

Symptom frequency

Please can you tick the relevant box by each symptom that you have experienced?

If you have experienced a symptom that is not on the list then please add it one of the empty rows at the bottom of the table:

Symptom	Frequency of symptom			
	Frequently (i.e. one or more times per week)	Infrequently (i.e. once or twice per month)	Rarely (i.e. only once or twice per year)	Never experienced
Impaired memory				
Blurred vision				
Physical fatigue after simple tasks that does not improve with rest				
Sore throat				
Headaches that feel 'normal'				
Feeling of light-headedness when standing up				
Headaches of a different kind				
Nausea				
Problems with physical balance				
Bloating of the abdomen				
Sensitivity to artificial lights				
Intolerance of certain foods or drinks				
Painful or sore joints				
'Cut glass' sensation in the throat				
Chills				
Slowed down thinking				
'Hangover' like feeling in head and body				
Cough				
Chest pain				
Painful or sore muscles				
Anxiety about being on your own				
Allergies to foods or drinks				
Pins and needles in toes				
Painful eyes				
Irritable bowel				
Flu like symptoms				
Mental fatigue after simple tasks that does not improve with rest				

Sensitivity to high frequency sounds				
Night sweats				
Sensitivity to low frequency sounds				
Feelings of anxiety that last for more than a day				
Diarrhoea				
Feeling irritable				
Restless legs or feet				
Panic attacks				
Prickly, sore or itchy skin				
Irregular heart beat				
Dizziness when standing up				
Fainting				
Pins and needles in hands				
Sensitivity to busy or disorganised noise				
Depressed mood that lasts for more than one or two days				
Unrefreshing sleep				
Fever/high temperature				
Sensitivity to day light				
Breathlessness				

Impact of symptom on daily functioning

Please can you tick the relevant box by each symptom to indicate its impact on your ability to carry out daily routines or specific activities:

Symptom	Impact of symptom on daily routine			
	Does not affect my daily routines or activities at all	I can carry out my routines or activities with a little difficulty	Makes it difficult to carry out my routines or activities	Prevents me carrying out routines or activities
Blurred vision				
Physical fatigue after simple tasks that Does not improve with rest				
Sore throat				

Headaches that feel 'normal'				
Feeling of light-headedness when getting up				
Headaches of a different kind				
Nausea				
Problems with physical balance				
Bloating of the abdomen				
Sensitivity to artificial lights				
Intolerance of certain foods or drinks				
Painful or sore joints				
'cut glass' sensation in the throat				
Chills				
Slowed down thinking				
'hangover' like feeling in head and body				
Cough				
Chest pain				
Painful or sore muscles				
Anxiety about being on your own				
Allergies to foods or drinks				
Pins and needles in toes				
Painful eyes				
Irritable bowel				
Flu like symptoms				
Mental fatigue after simple tasks that does not improve with rest				
Sensitivity to high frequency sounds				
Night sweats				
Sensitivity to low frequency sounds				
Feelings of anxiety that last for more than a day				
Diarrhoea				
Feeling irritable				
Restless legs or feet				
Panic attacks				
Prickly, sore or itchy skin				
Irregular heart beat				
Dizziness when standing up				
Fainting				
Pins and needles in hands				

Sensitivity to busy or disorganised noise				
Depressed mood that lasts for more than One or two days				
Unrefreshing sleep				
Fever/high temperature				
Sensitivity to day light				
Breathlessness				

How do you feel about your participation in this research?

The final questions are about your experience of this research. Please can you tick the box that applies to the statement in each case. There is also a space for your own comments but you do not have to write anything in this box unless you want to:

Statement	Agree	Neutral	Disagree	Comment
‘The nature of each visit was clearly explained to me at the start’				
‘I have found taking part in this research to be an interesting experience.’				
‘The researcher did not ask me anything that was inappropriate.’				
‘The researcher did not behave in an inappropriate way.’				
‘The research has not caused me to think or worry worry about myself in any undue manner.’				

‘My general mood and sense of well-being have not been made worse by taking part in this research.’				
‘At no time did I feel pressurised into any activity or discussion.’				
‘I have found taking part in this research to be a useful experience.’				
‘The researcher can contact me over the next year if there are follow up questions.’				
‘I am aware that audio-visual data that has been collected about me will be destroyed after the research period.’				

Please use this space to add any additional comments if you have them:

Signed: _____ **Date:** _____

Appendix 5: Standard debrief read to all participants at the conclusion of the study period:

Thank you for taking part in this study and allowing me into your home over the last six months and sharing and discussing your experience of ME/CFS with me. I hope that you found it interesting and that you were comfortable with all aspects of the research encounters.

Before I carry on, are there any immediate issues or concerns you wish to mention?

[Allow participants time to respond and discuss any concerns they raise as appropriate]

Okay. Thank you very much for that.

The final thing I must make clear to you is that if at any time from now on you have concerns about what will be done with the information you provided or if at any point you wish to have your participation in the research cancelled then all you need do is to ring the number provided on the information sheet, of which you have a copy to keep, and this will be discussed with you. If for example you request that you wish to withdraw from the research and have your data and recording destroyed then this will be carried out. You are under no obligation to the contrary.

Once again, are there any final things you would like to discuss?

[Allow participants time to respond and discuss any concerns they raise as appropriate]

Once again, thank you for taking part. I would now ask you to sign and date this debrief sheet as a record of finalising this research.

Name of Participant _____ *Date* _____

Appendix 6: exemplar extract of initial affective response

Immediately after each visit I recorded my affective response on a Dictaphone in my car. The following extract was recorded after my first meeting with Patsy.

‘Has an interesting relationship with her mother who she says late in the discussion may have been anorectic as a child. This ties in with Patsy’s relationship to food which is difficult in as much that she is extremely fussy about what she eats. Borderline eating disorder?

Lots of illness in her family. I.e. her own illness related to her proven kidney problem, her mothers and now her son James who is 27 and may be developing or have ME. She has been married from 21(?? FOLLOW UP) met her husband at uni and together ever since but she does not talk about him much in the discussion (FOLLOW?).

Patsy loves the outside and has only travelled in the UK; no foreign trips since 1987 (FOLLOW). She attributes this to financial constraints. Feeling a connection of *restriction* now at least between diet and money; she doesn’t lavish herself or family with things.’

Appendix 7: exemplar of affective response to video [from Hannah's second visit]

This is an extract from my affective response to the first viewing of Hannah's second visit. I recorded my thoughts as they came to me and any insights I had. The first two numbers relate to the time on the video and the last three digits are the transcript line numbers that match it. This enabled me to tie my affective response at each point with what was occurring or being said in the video.

30:13 346 This may lead somewhere significant; about taking water but not liking drinking it.

33:17 377 note her tone as she says that her brother had got her a present when it was her Dad was ill. This feels significant.

34:00 383 This Lumpy is really important. [Lumpy is a soft toy elephant]

34:44 395 It is important for her that Lumpy has been 'touched and held by all the precious people' and is not replaceable. This is very important.

34:57 398 Her description here of him as he will never be washed reminds me of the transitional object.

35:40 407 Lumpy stands in for her family if she goes away without them.

36:29 414 This is HUGE as it links ME with the rest of HER LIFE!!!! i.e. to her Dad and all that that implies!!

36:50 418 She says she still would take him now 'even though I don't need it' What a contradiction!!

48:07 535 May be a theme here about Hannah feeling the need to position herself in relation to authority??

Appendix 8: exemplar transcript section

The following extract is an example of transcript from John's fourth visit. He has been discussing the paper with me. Pause length is given in parentheses. Affective responses and observed shifts in body are given as comments. Capital letters in comments relate to thematic codes. Numbers in comments relate to specific lines. This enabled me to copy and paste coded lines into a subsequent document.

489 JB: Again about thirteen or fourteen cos I used to get Melody Maker and Sounds and I
490 would keep them and not throw them away then I would cut articles out and that sort
491 of thing. And eventually (1.0) it kind of took over you know all of these they () bits of
492 paper (say) () it's a reminder to do this and I must do that and I must () do this. You
493 know the house insurance and (1.0) write to this person and that would be a good idea.
494 And so there's a whole myriad of ideas and things to be done. And they're not () I'll
495 keep that bit of paper to remind me to do that.

496 JF: So there may be parts of you scattered around these bits of paper a memory thing?
497 Distributed a...

498 JB: A memory aid.

499 JF: A memory aid. Is that kind of part of it?

500 JB: On the face of it it's very much a memory aid thing. Um (>3.0) I mean thinking
501 about it again there's a reflection of fear of forgetting to do something. And feeling that
502 I () must do this. And it's um () important that if I don't retain this bit of paper then I
503 will forget to do it. And there's something about () I don't know validating the idea by
504 keeping the paper or something or () but the irony is I don't do it. The paper is almost
505 a substitute for actually doing it (3.0) Mmmm. I never thought about that before really

Comment [JF1]: 491(P since 13 or 14 he seems to have had this keeping paper thing; they all act as reminders but now that he admits to writing on them as well they take on another aspects also; which is what?

Comment [JF2]: 501(MEN he has a fear of forgetting to do something and the paper scraps help him alleviate the anxiety; the obsession is about forgetting and the compulsion which undoes this is keeping paper??),

Comment [JF3]: Rubs left knee with his hand

Comment [JF4]: 505(paper is a substitute for not doing what the paper is supposed to remind him to do), NOTE HOW HE GESTICULATES AS THOUGH HOLDING SOMETHING AND AS HE FINISHES THIS SENTENCE HE PUSHES HIS HANDS AWAY

Comment [JF5]: Reflective facial expression. Scratches head.

Appendix 9: exemplar of initial gathering of codes

This appendix illustrates how I gathered codes from across a set of transcripts into one place. The first tables indicate codes and hence themes for each visit. Codes were carried from one transcript to the next and back in an iterative process. Once the transcript had been fully annotated I was able to copy and paste each line that exemplified a code, as exemplified after the tables. The notes section at the bottom included anything that appeared salient that may not have been coded.

Continuing codes from first interview

Code	Theme
P	Perfectionism
DS	Drive to be stronger
LSF	The lack of a supportive frame
BCS	Being told by a credible source what she is
BV	Becoming self-validating
CTP	Conflation of thinking and psychosomatic processes

Continuing codes from second interview

Code	Theme
UM	Unreliable mother
G	Grandmother
DO	Different from others
WEA	Weakness from an early age
F	Father
T	Trapped [in flat]

P	The PEG as object and related ideas
W	Writing
F	Flat

Continuing codes from third interview

Code	Theme
MN	Meditation
OBE	Out of body experience
HH	Having to help others
CA	Credentials or achievement
BR	Breathing

Codes from fourth interview

Code	Theme
HY	Hyperactivity trace this in previous transcripts
NK	Neck
SF	Self

Instances of codes

Having to help others; 98(Well a very close friend who was trying to help me financially and in all sorts of ways. Was trying to help me with somewhere to live so I didn't have to come down these stairs)

Hyperactivity; 37(cos I suffer from the opposite of depression in a way this kind of hyper)

Meditation; 71(Well one of the things I've been doing that's very helpful is yoga exercises um because I believe in yoga. Because I believe it can heal. Um some things ha ha), see **356/BR**

Notes

95(J: So do you feel stuck inside a body that's not working? W: I have yes yeh.) at 101 she goes on to say (So that's what I was stuck with. So that's had some effect. That's made me feel trapped), **so this is a big metaphorical passage and makes me think that there is a link between being trapped in her body and being trapped in her flat**

Appendix 10: exemplar of metaphoric and metonymic events in the narrative

The following table illustrates how I utilised psychoanalytic ideas to notice aspects of discussion with ME sufferers that appeared significant in metaphoric or metonymic processes. Codings such as TS1 relate to the transcript number for that individual.

Process	Suggested significance	Example from data sets with notes
Omissions	Barred access to a given domain	TS1 Absolute absence of the literal father from transcript with Whimsy.
Lengthy hesitations	Resistance to communication between domains	TS2. I ask Whimsy about the circumstances of her car crash. She replies “ <i>But they the two passengers my passenger and the umm (4.0) the driver (0.5) were both about nineteen years old.</i> ”
Slips of the tongue	Interference between domains, metonymic substitution. These would be explained in terms of Freud’s ‘parapaxes’.	John TS1 is explaining how his Mum and Dad had split up but some years later decide to get back together. John has had animosity for his Dad since childhood and states an allegiance to his Mum. However, he says “... <i>which seemed great on the face of it. But (2.0) I was (0.25) in some respects it was great. But in other respects I was () I I don't like my father. I didn't like the thought of them getting back together again. Particularly as he is quite domineering and oppressive I didn't want to see my mum back in an environment where she might be happy.</i> ” ‘Happy’ substitutes for ‘unhappy’.
Jokes, humour	Metaphorisation, partitioning of metaphoric processes in general	Bruce TS2 is explaining how gardens evolve over time “... <i>So when you start looking at a garden in those terms in historical terms then they become really quite complex cultural artefacts. Now. The people I work for at the moment if I tried to talk to them like that you know it'd be (touches his forelock) 'get back in your box.' 'Yes master.' For fuck's sake! You know. And it always appals me that the people who actually have control who own these bright and cultural artefacts are ignorant, arrogant, selfish (laughing) and lacking in any sort of () social responsibility.</i> ”
Inappropriate laughter and humour	Barring between domains	TS2 Whimsy is describing how her mother had tried to abort her and says “... <i>Even though recently apparently she'd thrown herself down the stairs. So it seems when I was born ha ha ha I was already kind of () not umm not () I was already kind of knowing I wasn't wanted.</i> ”
Denials, uncertainties	Barring between domains	TS4 We are discussing her divorce and whether it links to her ME. She states “ <i>And some friends at first thought probably I had a broken heart. That's why I couldn't speak and that's why I had a () um (1.0) emotional () breakdown. Maybe. I don't know.</i> ”

Affective shifts	Sudden activation of specific domains in communication suggesting translation between past and present	TS1 Whimsy has explained how she was driven to be stronger as a child. I ask her what was doing the driving. She explains she can't answer that but it involves 'childhood trauma'. I sense an affective shift and switch to asking her if she had any brothers or sisters and then describe another participant's experience. Whimsy exclaims "Phweeeew! Really!" but this is out of kilter with what I described. My affective notes record that <i>this feels like an affective rebalance caused by the actual affective event which was me triggering her memory of trauma by my asking if she had siblings</i> . Whimsy then proceeded by explaining how she was adopted.
Insight, realizations	New communication between domains or new metaphorisation	John TS2 I have been asking about the significance of the cinema. He states <i>"...There's something (>3.0) there's something safe about it I guess in that respect and you're anonymous as well. Me I'm not important to the people around me what's important is what's going on on the screen. So there is something I think about the darkness and combine () the safety of it. I hadn't thought about that before ... [tails off]"</i>
Resistance [to ideas]	Partitioning of certain metaphoric processes	ME sufferers refute or reject my observations or insights.
Intersubjective resonance	Strong communication between, similarity or bridging between individuals metaphoric systems	John TS2 John has discussed how he hoards paper(s) and I feed this back to him how I have felt it. He replies immediately and affirmatively "Absolutely!" My affective notes record that <i>John might have felt understood at this point</i> .
Narrative shifts	Metonymic substitution of content in one domain for content in another.	Sudden jumps in topic to something apparently disconnected; Les TS2 'L: <i>That's why yesterday afternoon I felt (1.0) all sort of () all () don't know () I thought I'll go for a little walk see if that does anything and it did () it done the trick. (3.0) // Cos ah () the cemetery is full actually.</i>
Temporal confusion	Translation and barring of past and present	TS1 Across a short passage Whimsy has extreme difficulty establishing the chronology of her collapse at work, her car crash, her pregnancy.
Inconsistent logic	Metonymic substitution as above or access barring between domains	For instance that Whimsy illogically fears her neck will break.
Interpretation	Bringing together metaphoric processes into a cluster	Whimsy throughout interprets ME in terms of 'energy blocks' and 'energy' is used metaphorically in various ways.
Marked bodily shifts and gestures	Metaphorisation, metonymic translation between domains i.e. somatic to cognitive	TS3. We have meditated and she explains her experience has been different. I ask here where ME is and the video shows her suddenly rub her neck and she states <i>"I'm very tired. And my neck is um quite challenging me."</i>

Appendix 11: pen portraits for sufferers taking part

Participant background

Patsy

Age at time of data collection: 54

Date of formal ME diagnosis: 2007

Onset of ME/ME like symptoms and events implicated by participant: Patsy suffered reactive arthritis at age five and seems to have had an ME-like illness age 16. She has suffered life-long thyroid and adrenal problems and had a nephrectomy when she was 38. In 2005 Patsy began to suffer headaches; this is where she positions the start of her ME. In the year leading up to this she implicates two triggering events: firstly, having to negotiate looking after her 84 year old mother in law who lived some 15 miles away and subsequent hospital visits whilst she was dying with bowel cancer. Secondly, having to look after her mother after a tonsillectomy. At this time she crashed in terms of energy. By 2011 her energy had flagged and interfered with her work.

Domestic situation: Patsy married in 1977 to John. She had her daughter [Zoe] in 1980 and her son [Joe] in 1984. Patsy and John met at university and have been together since. John originates from Somerset and they settled in the area when they married. They have owned one other house besides her present bungalow. Patsy's family moved many times when she was a child; from Cheshire down to Berkshire. This was primarily due to her father's ill health.

Significant relationships: Several individuals are described in depth; most significantly Patsy's mother who had 'major digestive surgery' before age 3 months, fractured her skull in a fall at age 2 years, as a teenager she seems to have suffered anorexia and subsequently throughout her life had several psychiatric interventions and ECT. She also underwent several operations on her spine, bowel and bladder. Basically, her Mum spent her life suffering one illness or another. During the research period Patsy's Mum underwent a further operation and died [age 82]. It appears the surgeon perforated her bowel and this went undetected; a coroner's inquiry is being held, with the conclusion due just after the last time I met Patsy.

Patsy's father is described in less detail. Patsy felt loved by him though he was 'emotionally undemonstrative'. He had worked for the coal board but developed jaundice. Significantly, her father and his family were 'country' and inculcated in Patsy a love of the outdoors and nature. Her mother's family was 'city' and Patsy seems to have been less close to them. Patsy's parents split up 'not long after [she] was married'.

Patsy's son Joe is 27 and began a computing degree at university but stopped half way through to [successfully] publish a computing manual. He subsequently lived in London and Reading but seems to have always suffered 'ME like symptoms'. Now he lives back at home ostensibly for health reasons. Patsy believes there is a family

disposition to poor adrenal function that is at the root of this. I feel that Joe also shares the same slightly asocial personality as Patsy.

Education and career: Patsy completed science A' levels and then a psychology degree and then entered the teaching profession at secondary level. This choice based on what she could fit around a family. Her first post was in a community care school but this was too demanding; given she was pregnant at the time. She was made redundant from her most recent post, in March 2011. This resulted from a combination of low energy [ME] and increasing ethical concerns with teaching. She has remained unemployed since but did purchase the rights to a sowing-kit business which now hopes to run as a low-level concern.

Participant background

John

Age at time of data collection: 49

Date of formal ME diagnosis: 2005

Onset of ME/ME like symptoms and events implicated by participant: John reports having experienced low energy levels and fatigue since early childhood. In later life as an adult he was found positive for hepatitis C and posits this as a possible foundation for subsequent ME. The only event which he can link potential hepatitis infection to is when he had wisdom teeth out around the age of thirteen. John did not suffer an acute phase of ME; his symptomology is typical and the main feature is fatigue and low mental and physical energy. This is exacerbating albeit slowly over the last decade or so.

Domestic situation: John lives alone in a single bedroom fourth floor Georgian flat. He has owned this flat for some time but did not plan to live there as long as he has. The flat may lack enough physical space for John and this is certainly the case in terms of his desire to find a larger home where his son can stay.

Significant relationships: John has never been married. He lived for a short while with a girl in London after university in his early twenties and since then appears to have had several short term relationships. Around 2000 he met a Polish woman who was married and embarked on an affair with her. This resulted in them having a boy, James, who is now around twelve years old. James lives with his mother in the York and John visits him when he can. John is reticent about James staying in his flat due to lack of space and the general 'environment'.

John grew up with a mother and father and two sisters; Rachel who is eight years younger and Zoe who is eighteen months younger. John describes his relationship with Rachel as not close; she left home at age 15/16 to live with her boyfriend. John states that he would on occasion hit Zoe. Temperamentally, Zoe is like John's Dad and this is

cited as one reason for their lack of closeness. John was closer to Rachel as she was less aggressive but since she moved to America they have become less close.

John's father is recurrent in the data and is described as hostile, domineering, aggressive, unable to communicate with John, intellectual and emotionally suppressing. He appears to have had a significant impact on John's development. John's mum is described as subservient, a homemaker and not intellectual. John has had a difficult relationship with his father and this is ongoing.

Education and career: John completed A' levels with some difficulty and embarked on a degree in geophysics but did not graduate. He then embarked on a career in the RAF as a navigator. After around eighteen months he was dropped from navigator training; John cites not being able to keep up with the increasing need for rapid thinking. He then joined the military police and remained in this branch for eighteen years. During this time John was an officer in charge of up to fifty individuals and was posted around the world roughly every two years.

John left the RAF at age 43 as he felt he could no longer cope mentally or physically. He worked part time for pension credits [but eventually was made redundant] and in his local cinema a couple of evenings per week. He has now been unemployed for some years and works part-time voluntarily in his local Oxfam. He also volunteers at his local cinema during their annual film festival.

Participant background

Freya

Age at time of data collection: 43

Date of formal ME diagnosis: December 2010

Onset of ME/ME like symptoms and events implicated by participant: Onset of ME like symptoms occurred in 2004 and was acute in that Freya was out walking in the countryside and was overcome with tiredness and a sore throat and had to go back to her car. The most significant ME symptoms have been peculiar headaches, spongy feeling developing into myalgia in the thighs and low energy levels. The symptoms have stabilised into clear-cut trimonthly cycles of relapse/remission. There are no clear triggers to exacerbations.

Since childhood Freya has had several illnesses which she mentions but does not directly implicate in ME: grumbling appendix/appendicitis as a child and then intermittently [finally removed age 24], IBS diagnosis around age 6, glandular fever around the same age, acute becoming chronic back pain around age 35 [cured overnight with a copper bracelet], depressive episode in her early thirties. She describes herself as having depressive tendencies.

Domestic situation: For the last seven years, Freya has been in her first long term relationship; with Paul. Paul is a freelance music teacher. They live in an old house with no children but several small pets. Freya describe she house as generally dark and not conducive to light or being able to draw energy from it. Freya has lived in many places in England both before and with Paul. She estimates having moved nearly every year for fifteen years.

Significant relationships: Freya has a Mum and Dad who divorced when she was 18. This has had a significant effect on her. Her Mum suffered post-natal depression with Freya and was in and out of hospital throughout Freya's childhood. Freya has a sister, Julie, who is 5 years younger than Freya. Julie has suffered from eating disorders and ongoing OCD since mid/late teenage and has received psychiatric intervention. She is described as having an addictive personality and had not worked for the last ten years. Julie and Freya's relationship seems to be marked by ambivalence. Freya is very close to her Dad and identifies strongly with him. She describes a 'split' in the family with Julie aligning with her Mum and Freya with her Dad. Freya also mentions a grandmother who she was very close to. One of her objects was a cupboard she obtained from her Gran when she died. Her Gran seems to have provided some sense of ongoing stability for Freya that was absent from her other relations.

Education and career: Freya describes herself as fairly academic; growing up in Essex and attending a grammar school [Julie attended the local comp]. Freya passed A 'levels and then a degree in psychology and maths at Royal Holloway. She enjoyed her time in London and engaged in many enjoyable social activities. After graduation she joined an accountancy firm which she describes as a mistake, but passed her accountancy exams after three years and worked in that line for four years. She then moved into human resources for a couple of years and worked in New Zealand for a few months. On returning, she completed a master's degree in Manchester and then worked in occupational psychology; which she has done for the last ten to twelve years. This work appears to be varied; which she has found interesting but demanding. She has worked in places such as Syria and Egypt and often travels around England from place to place; occasionally having to cover 800+ miles per week.

Participant background

Hannah

Age at time of data collection: 25

Date of formal ME diagnosis: March 2004

Onset of ME/ME like symptoms and events implicated by participant: Hannah's ME onset occurred when she was age 17, in 2003, and she has no recollection of preceding infection or acute triggering event. However, she states that whilst at college she did experience bad headaches for some time and '*experienced a few strange things*' and '*was in town once and just felt really sort of weak and like wobbly*'. Her

ME was diagnosed at a specialist hospital approximately 2 years after onset. Hannah now considers herself to be over the worst phase of ME but suffers ongoing residual effects and is reticent to talk of a full recovery to health. At the time of onset Hannah had embarked on A' levels at a local college. She was enjoying these courses but had to suspend them due to ME. Prior to ME, Hannah considers her life to have been 'normal'. Hannah experiences anxiety in various forms. She reports this explicitly. For example, she tends to avoid social situations that involve her having to eat in front of others. She avoids crowded places and large parties of people.

Domestic situation: Hannah lives alone with her Mum in an old stone house in a small village. Her Mum does not work. Hannah feels safe and secure whilst in this house and yet the world beyond presents as a place where she experiences the anxieties outlined above. Hannah's house has been her family home for some years before her birth.

Significant relationships: Hannah describes her family as 'close'. She is very close to her Mum, who is in her late fifties. Hannah talks of family members in a positive way and they have been supportive of her before and during ME. Besides her Mum, Hannah has two brothers; 8 and 5 years older than herself. She has been especially close to the oldest brother who, by her admission, took on the role of surrogate father when she was very young; *'closer than probably what people would think normal'*. The reason for this was that her father developed an extremely rare condition [Schnitzler's syndrome] when she around three years old. This appears to be an heterogenous syndrome incorporating neurological and motor effects. The father was confined to a wheelchair at periods and his health needs affected the family in various ways. As such, the eldest brother took the role that the father would have had but despite this Hannah was very close to her father, citing the fact that as he was always at home she spent more time with him than her peers might have. Hannah views this as a positive thing. Her father died at home in 2005 at age 71. This may have been due in part to the syndrome but Hannah explains that besides that he may also have had cancer and he was of advanced years Her youngest brother lives in the local area but the older brother now lives near London and returns every couple of weeks.

Education and career: Hannah is currently studying for a youth and childhood studies degree with the OU; she is in the fourth year of a six year course. This mode of study suits her but Hannah struggles with the idea of full-time employment and cites ongoing fatigue and fear of symptom reoccurrence by way of explanation. After a period of improvement from symptoms Hannah volunteered with a local charity; once a week at an after school club. These shorts bursts of activity allowed her plenty of time in the week to recover. Eventually she was well enough to work three or four sessions per week but recently the charity has lost funding and she is back to one session per week. Hannah wants a *'quiet life'*. She wants two children and to do *'normal things'*. She does not consider herself adventurous and desires a family and a home and perhaps a job working with children.